

School of Occupational Therapy and Social Work

**Creating welcoming communities:
Indonesian people with disabilities speak out**

Dini Widinarsih


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Doctor of Philosophy
of
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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature: 

Date: 2 July 2018

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The years during my PhD journey were very onerous. My beloved father passed away when I had just started my journey. Then my beloved eldest brother died of a heart attack just three days before I flew to Perth to start my course. My beloved mother passed away when I was struggling to finish this thesis as my scholarship and my student visa were nearly expiring. My eldest sister, her husband, and my niece passed away during the thesis revisions. I was in so much pain and was not sure I would be able to cope. I am extremely grateful for the goodness of many people around me who directly and indirectly helped me. I therefore want to express my appreciation here.

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Abstract

The main focus of this research is to understand the ways in which awareness-raising strategies can be used to increase understanding of people with disabilities (PWD) as active members of Indonesian society. This study is a qualitative Participatory Action Research (PAR) project, involving 43 Indonesian persons living with physical disabilities as participants. This is the first Indonesian PAR study co-produced with PWD.

The findings indicate current disability awareness transmits messages that Indonesian PWD are passive, incapable and burdensome for Indonesian society. The participants identified that one crucial strategy for raising positive disability awareness is the development of disability awareness videos based on the Social Model of disability. Consistent with PAR processes, this study includes the development of a video, with PWD taking an active role in the video-making process. Their onscreen representation presents a positive image with affirming language, and the video covers three types of messages: informational, instructional and affirmative. Thus, the video developed as part of this PAR has three elements for awareness raising: knowledge, skill, and values to be internalised by audiences.

The key contributions of this study to the field of disability studies include: firstly, a broader definition of disability awareness and disability awareness-raising for Indonesia; secondly, the development of disability awareness video guidelines; and thirdly, a disability awareness video. These were all substantial and represent the creation of original knowledge involving Indonesian PWD in the spirit of the Social Model of disability through PAR in a non-Western context. No similar PAR studies with PWD in Indonesia have been completed. The participants recommended that creating a welcoming community is a social responsibility of all members of Indonesian society.

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*) Notification / Explanatory Statement

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CHAPTER ONE

INTRODUCTION

This study is driven by the main research question: In what ways can awareness-raising strategies be used to increase the understanding of people with disabilities (PWD) as active members of Indonesian society? This question is addressed by three key sub-questions: (1) What are the realities of an Indonesian PWD's life in Indonesia? (2) What is the state of current disability awareness in Indonesia? (3) What are the research participants' thoughts and ideas on the development of disability awareness-raising strategies in an Indonesian context?

This chapter provides a brief background to the study. It is followed by a presentation of the research questions and objectives, the research approach and methods, the significance of the study, and the key terminology used in this study. The chapter concludes with an outline of the thesis.

1.1. Background and context

In 2010 the estimated number of Indonesian people with disabilities (PWD)¹ was 3,352,293, which equates to 1.38% of the total population of Indonesia. This estimation was based on the national census conducted by the Indonesian Bureau of Statistics (IBS) in 2006 (United Nations Economic and Social Commission for Asia and the Pacific/UN ESCAP, 2010, p. 34). Since 2010, it can be assumed that the number of Indonesian PWD has increased as a result of several natural disasters (Masduki, 2011, p. 48), continuing malnutrition, and traffic accidents in many areas over the years. Indonesia is a country with a range of disability risks (Irwanto, Kasim, Fransiska, Lusli and Siraj, 2010, p. 0) given the presence of natural disasters such as floods, earthquakes, tsunamis, landslides, volcanic eruptions and forest fires. Indonesia is also vulnerable to malnutrition and traffic accidents.

¹The acronym PWD is used throughout this thesis to interchangeably refer to a **person with a disability** and **people with disabilities**, in order to conserve space.

Most of the PWD living in different parts of Indonesia face complex issues in their daily lives. Across the country, they experience difficulties related to access to public areas such as healthcare and education facilities, gaining employment, and other services that many people without disabilities take for granted, such as going shopping and taking public transportation. Many of these difficulties derive from prejudice, stigma, marginalisation, ignorance, indifference, and a lack of concern by the government, employers, health providers, neighbours and schools (Byrne, 2002; Fuad, 2008a, 2008b; Komardjaja, 2001a, 2001b; Sirait, 2008). Due to these attitudes, Indonesian PWD are confronted with a level of discrimination and injustice that affects their social inclusion into society.

The discrimination and social exclusion faced by Indonesian PWD also imply that Indonesia still does not adequately promote and enact the aims of two consecutive decades devoted to the rights of PWD: the Asian and Pacific Decades of Disabled Persons (1993-2002 and 2003-2012). Both of these initiatives encompassed the idea of 'an inclusive, barrier-free and rights-based society for PWD' (UNESCAP, 2002, p. 3). It was mutually agreed by UN member states that the growing population of PWD in the Asia-Pacific region, which includes Indonesia, requires a strong focus on their rights.

The Indonesian Government's commitment to promoting the human rights of PWD can be evidenced by the number of regulations relevant to and concerning PWD (Irwanto *et al.*, 2010, pp. 21-26), namely:

- The 1945 Constitution, Article 28 D (1);
- Law Number 4 (1997) concerning persons with disabilities;²
- Law Number 39 (1999) concerning human rights;
- Law Number 28 (2002) concerning constructing buildings;
- Law Number 20 (2003) concerning the National Education System;
- Law Number 10 (2008) concerning elections;

²During revision of this thesis, Law Number 4 of 1997 concerning disabled people was considered 'no longer appropriate to the paradigm of the needs of persons with disabilities' and was superseded by Law Number 8 of 2016 concerning people with disabilities (Ministry of Social Service of the Republic of Indonesia, 2016, p. 2).

- Government Regulation Number 43 (1998) concerning social welfare improvement efforts;
- Government Regulation Number 36 (2005) concerning the implementation of the regulations of Law Number 28 (2002) concerning constructing buildings;
- The Ministerial Public Works' Decree Number 468/KPTS/1998 concerning the technical requirements of accessibility in public buildings and environment;
- Presidential Decree Number 8 (1999) concerning coordination and control institutions for the improvement of the social welfare of PWD;
- The Ministerial Transportation Decree Number KM 71 (1999) concerning accessible facilities for PWD, the elderly and the sick in transportation infrastructure.

A recent regulation was Law Number 19 (2011) concerning the legalisation of the United Nations Convention on the rights of PWD (CRPD). This law was issued to incorporate the ratification of the CRPD into a domestic legal instrument. Indonesia signed the CRPD on March 30, 2007, and ratified it on November 30, 2011 (United Nations Treaty, 2012, p. 2). These measures were a significant step taken by the Indonesian Government to strengthen Indonesia's commitment to promoting the human rights of PWD and the aims of the Asian and Pacific Decade of Disabled Persons 2003-2012 (UNESCAP, 2002, p. 3).

Tsaputra (2011, paragraph 8), an Indonesian activist with a disability who holds a Masters degree from an Australian university, confirmed that the ratification and what the Government had done so far to enhance the conditions of PWD in this country should not be dismissed. Nonetheless, the signing and ratification of the CRPD by the Indonesian Government will not, on its own, ensure its full implementation (CRPD, 2007, p. v; Tsaputra, 2011, paragraph 8). Implementation of the CRPD to ensure full and equal enjoyment of all human rights by citizens with disabilities involves determination and active participation of all parts of society.

Equality for PWD and their inclusion into society require increased awareness of the needs and rights of those with disabilities. This is due to the fact that 'the existence of human and civil rights alone cannot guarantee the full and equal rights of citizens with disabilities, and their inclusion requires a variety of 'enabling' strategies (Stevenson, 2010, p. 37). The practicalities of ensuring the rights of and social justice for PWD have proven to be challenging. There are notions of how to address these challenges, but they all support the same idea that the best way to make decisions and choices on PWD inclusion strategies is to include PWD in decision-making processes (Stevenson, 2010, p. 47; Barton, 1989; Longmore, 2003; Ghai, 2003, pp. 20-27; Tomlinson & Trew, 2002). This involves tangibly responding to the disability movement's slogan and motto of the International Day of Disabled Persons in 2004: 'Nothing about us without us' (Stevenson, 2010, p. 47). However, this motto does not mean that people without disabilities are not allowed to participate in the disability movement and should be excluded because they have not experienced disability. 'One does not have to be disabled to be able to make a positive contribution to the disability movement' (Radermacher, 2006, p. 48).

My determination and engagement in this field, and specifically efforts to raise awareness of the needs and rights of PWD, are based on my commitment to, and faith in the philosophy of valuing all people (Wolfensberger, 1992) and the human rights and social justice aspirations upheld within the discipline of social work (International Federation of Social Work, 2000). Valuing all people involves respecting the rights of PWD, accepting equal participation of PWD in everyday life, ensuring that they can exercise and enjoy their rights, and preventing any discrimination or oppression that may breach those rights. As affirmed by Ollerton & Horsfall (2013), discrimination on the basis of disability implies that having a disability is related to a person's worth or value, which breaches universally accepted human rights (p. 618). My commitment and understanding stem from my background, where I was raised in a big family that constantly asserted the philosophy of equality. My great-grandfather used to work with a rehabilitation centre and nursing home for the visually impaired in Bandung, West Java during colonial times, while my grandmother was an activist for the disadvantaged in Bandung. My mother worked as a primary

school teacher before leaving her job to accompany my father, who was in the Indonesian National Army, to relocate to Jakarta. My great grandparents, grandmother and mother have influenced my interest in social work and the disability field—which has been an undervalued field of research and activism until now. There is still very little knowledge about disability awareness in Indonesia; however, my great-grandfather, grandmother and mother have been my role models and they have encouraged me to be engaged in raising disability awareness in Indonesia and to be part of the fight against discrimination and oppression.

All research is subjective, value-laden and non-arbitrary, therefore, the personal values and motivation of the researcher should be revealed and acknowledged before the research starts (Creswell, 2013, pp. 46-47) as a way to ensure rigorous and ethical research practice (Guillemin & Gillam, 2004, pp. 277-278). In accordance with this, I have explained, in the previous section, my personal history, which drives my commitment and interest in the field of disability. In the following section, I will reveal my personal experience in engaging in an effort to raise disability awareness in Indonesia.

Before starting my PhD in Australia in 2009, I worked at the Disability Studies Centre, Faculty of Social and Political Sciences, University of Indonesia (DSC-UI) from 2006. The DSC-UI was initiated by a small group of alumni of the University of Indonesia, whose membership comprised those with and without disabilities. All of the alumni with disabilities had graduated with a postgraduate degree from universities overseas with scholarship support from international funding bodies. The DSC-UI commenced pioneering efforts to build an inclusive society by providing disability awareness through extension training for the community, starting with the University of Indonesia's *civitas academica* (a term used to refer to an academic community consisting of students, academic staff and non-academic staff). One of the breakthroughs from this initiative, which had previously never happened in Indonesia, was that the training team consisted of PWD and persons without disabilities. The team trained students and academics, as well as non-academic staff of the University of Indonesia.

The evaluation by participants of this ongoing action revealed that the delivery of the training programmes would have been better had they been complemented by audio-visual material/media. In response, the DSC-UI then established a partnership with a local television station in Jakarta, known for their humanitarian values, to produce documentary videos on Indonesian PWD. These videos could have later been used for the DSC-UI's disability awareness training but unfortunately, in a feedback session on one of the pilot productions, the DSC-UI expressed the view that the documentary produced could not be considered a disability awareness video. It was simply a compilation video of inspiring stories of people with disabilities. The project had not yet been completed by the time I went to Australia to start my course in 2009. This feedback made me realise that there was a need to explore further the methods of disability awareness and relevant audio-visual instruments for disability awareness in Indonesia. Apparently, there was a lack of knowledge and media/materials about disability awareness in Indonesia. Very few documentaries on disability in Indonesia have reached international audiences or the academic community at an international level. Thus, this study is inspired by the DSC-UI's aim to promote a more inclusive society to overcome the shortcomings of the existing disability awareness strategy in Indonesia, and the literature on disability in Indonesia at the international level.

Although there are currently only a few documentaries on disability awareness in Indonesia, there are several research projects, which have been conducted by Indonesian researchers with disabilities, which cover complex issues experienced by Indonesian PWD. These include a study of PWD survivors of the 2004 tsunami in Aceh, who continue to face many problems due to a lack of accessible facilities and aid (Masduki, 2011, p. 54); a project on complex issues regarding employment or the 'right to work' for PWD survivors of the 2006 earthquake in Klaten, Central Java (Suharto, 2011, pp. 25-39); a study of the complex issues regarding the legal rights of PWD pertaining to justice for victims of violence in two cities in Central Java (Syafi'ie *et al.* 2014, pp. 153-159); and a research project on discrimination, rejection, and the difficulties PWD face with regard to accessing education, health services and employment (Syamsudin, 2010, pp. 22-30).

Research evidence in Western countries indicates that various disability awareness-raising activities (Ollerton & Horsfall, 2013, pp. 626-627), especially those which incorporate audio-visual materials such as film (Schwartz, Blue, McDonald, Giuliani, Weber, Seirup, Rose, Elkins-Albuhoff, Rosenfeld, & Perkins, 2010, p. 847) and video (Tavares, 2011; Ison *et al.*, 2010; Disability Service Commission, 2006), positively increase awareness of PWD. Research also shows that in this technological media-influenced age where many people rely on visual images and are more visually literate, audiovisual materials, in comparison with written materials, can be a more appropriate format to reach wide and diverse audiences (Cruze, 2000, p. 3; Schwartz *et al.*, 2010, p. 847). Several research publications also reveal the importance of video/film-making through participatory action research (PAR), which also informs well-known research methodologies and methods (Hume-Cook, Curtis, Woods, Potaka, Wagner & Kindon, 2010; Kreitzer, Abukari, Antonio, Mensah, & Kwaku, 2009; Parr, 2007). Further details on PAR with videos will be presented in Chapter Three.

The remaining challenges are to transfer the above-mentioned research results to very different contexts such as Indonesia and to determine the perceptions of a purposive sample of Indonesian PWD about how to best develop engaging disability awareness-raising activities that maximise the potential to improve people's understanding of the lives of PWD. To meet these challenges, this study involved collaboration with a purposive sample of Indonesian PWD in a way that accommodated the voices of people with lived experience of disability in Indonesia. The details of this purposive sampling will be elaborated on in Chapter Three.

1.2. Research questions and objectives

This study is driven by the main question: In what ways can awareness-raising strategies be used to increase the understanding that PWD are active members of Indonesian society? This question is complemented by three key sub-questions: (1) What are the realities of an Indonesian PWD's life in Indonesia? (2) What is the state of current disability awareness in Indonesia?

(3) What are the research participants' thoughts and ideas on the development of disability awareness-raising strategies in the Indonesian context?

Accordingly, this study has three objectives based on the above-mentioned research questions. This study collaborates with a purposive sample of Indonesian PWD to achieve these objectives. Firstly, the study aims to describe and analyse the realities of PWD life in Indonesia. Secondly, it aims to explore and analyse the key issues related to current disability awareness in Indonesia. Thirdly, the study seeks to develop a disability awareness raising strategy, as proposed by the research participants.

In order to achieve the objectives of this study, I carried out a literature review and set out a schedule for the research project. The literature review was an important starting point to give me a clearer reference to determine the research approach, to locate the position of my research in the field of study, and to set up the criteria for selecting the research participants. It was also important to set out a clear and realistic schedule in designing my research within the limitations of the study's resources.

1.3. Research approach and methods

Taking into consideration the background, questions and objectives of this study, PAR was employed as a principal research approach. This section describes my rationale for choosing PAR and qualitative research, and also outlines the research methods. Further description of this issue is presented in Chapter Three.

There is general agreement in the literature that one of the most appropriate strategies to address the rights of, and social justice for PWD, with regard to disability awareness-raising, is to conduct participatory research (Stevenson, 2010, p. 37; Bloomberg & Volpe, 2008, p. 9; Gilson & DePoy, 2002, p. 163). This is because PAR is mostly driven by social contradictions or problematic practices that trigger a 'need to know in order to bring about desired change' (Wadsworth, 1993, p. 1).

Historically, research on disability has served to marginalise PWD because it mostly focused on the functional limitations or consequences of impairment, while the voices of PWD and their experiences and existence were excluded and not considered as a valuable part of the research conducted by experts or other professionals (Abberley, 1987, p. 5; Barnes, 2003, p. 4; Barnes & Mercer, 2010, pp. 18-24; Kitchin, 2000, p. 29; Valade, 2004, p. 38).

Thus, employing PAR is considered in this study as a response to the international consensus that PWD, who have previously been systematically excluded from knowledge generation, should be involved as active participants in the research process or programmes about them (Ghai, 2003, pp. 20-27; Brydon-Miller, Kral, Maguire, Noffke & Sabhlok, 2011, p. 389; Stevenson, 2010, p. 47; Tomlinson & Trew, 2002). Consequently, I believe that applying PAR allows this study to capture the perspectives of a purposive sample of Indonesian PWD, and include them as valuable and active participants by respecting their 'intimate' life experience as a valuable source of knowledge.

A qualitative approach and design was employed in this study. PAR is qualitative by nature, as it emphasises dialogue and knowledge generation through interaction and genuine collaboration (Brydon-Miller *et al.*, 2011, p. 389; Reason, 1998, p. 270). Moreover, a previous study revealed that qualitative methods are strongly demanded by all research participants who are PWD because they provide the opportunity to express and contextualise their true feelings. PWD are considered as valuable research participants (Kitchin, 2000, p. 43). Another study in India reported that 'there is a significant lacuna of research evidence which captures the thoughts, feelings and perspectives of PWD themselves' (Singal, 2010, p. 420). Employing qualitative PAR also means concurrently exercising the philosophy of equal rights and inclusion of PWD. It has been acknowledged that 'qualitative research is suited to promoting a deep understanding of a social setting or activity as viewed from the perspective of the research participants' (Bloomberg & Volpe, 2008, p. 8). Minichiello and Kottler (2010) also argue that qualitative research embraces and honours subjective experiences - not only those of the informants and participants, but also that of the researcher. Minichiello and Kottler (2010) also

emphasise that 'the socially constructed knowledge which occurs within a personal and cultural context is not necessarily a weakness, but rather a strength of the qualitative approach, particularly if the researcher engages in rigorous self-reflection and careful analysis' (p. 8).

Research participants were Indonesian PWD who were recruited using a purposive sampling method following Wadsworth and Epstein's criteria for participatory change (2001, p. 8). Although they were recruited via information and referrals from disability-led organisations, they participated in the study as individuals and not as affiliates or representatives of particular organisations (Mulling, Wali, McLean, Mitchell, Prince, Thomas & Tovar, 2001, p. 87)

Data was collected using several methods commonly used within qualitative research (Creswell, 2013, p. 159) and PAR (Kindon, Pain & Kesby, 2010, p. 17). These included individual in-depth interviews and group discussions, video-making, and video sessions. The use of different methods and various participants allowed for the triangulation of data, which ensured the credibility and quality of this qualitative research project (Lincoln & Guba, 2011, p. 296)

Qualitative data analysis was used to analyse all information gathered from interviews and discussions with the research participants. The analysis followed the process described by Creswell (2013, pp. 182-188) and Braun and Clarke (2006, p. 87), who refer to this approach as thematic analysis.

1.4. Significance of the study

It is hoped that this study will have theoretical and practical implications for the fields of disability research and policy in Indonesia. The theoretical significance of this study is to contribute to discourse on the Social Model of disability, disability awareness, and PAR on disability issues in a non-Western context, namely Indonesia. The practical significance of this study is the production of knowledge regarding appropriate disability awareness-raising activities which may serve as a complementary tool for Indonesian PWD advocacy efforts.

1.5. Key terminology used in this study

1.5.1. Disability

This thesis uses the term disability to describe a bio/psycho/social impairment. This is in line with the International Classification of Functioning, Disability and Health (WHO, 2011), which describes disability as the umbrella term for impairments, activity limitations, and participation restrictions that refer to difficulties encountered in any or all three areas of functioning: body functioning and structure; activities and participation; and environmental factors (WHO, 2011, pp. 4-5).

1.5.2. Person with Disability/People with Disabilities/PWD

This study uses the term 'person with disability' (or in plural: people/persons with disabilities), which is commonly abbreviated with the acronym: 'PWD'. These terms are used in this thesis to represent my alignment with, and affirmation of the concept of 'person first language', which 'emphasises the common status of person-hood of the subject, and establishes an attitude of respect and acceptance of the individual's differences and complexity' (Shapiro, 2000, pp. 70-71). In fact, the term PWD, which denotes a quality added to someone's personhood, is preferred by many people rather than the term 'disabled person', which indicates a 'reduction of the person to the disability' (p. 71). However, the term 'disabled' has inevitably been written in several sections of this thesis due to quotations from authors or research participants who prefer to use this term. For example, disability advocates in the United Kingdom, namely Michael Oliver, Paul Hunt, Vic Flinkenstein, and Tom Shakespeare, prefer to use the term 'disabled person/people' to emphasise the ways in which the world does not accommodate people who have had imposed on their impairments and it is in fact the environment which disables them. Accordingly, these advocates believe that the disabling experience of living with an impairment is very much a part of an individual's identity and it cannot be removed from the lived experience of that person. They consider that the use of 'people first' language by a disabled person may constitute a denial of their impairment, and if used by professionals suggests

that they do not want to recognise the disablism outlined in disability discourse. (Bricher, 2000, p. 785).

Although I understand and agree with the justification for using the term 'disabled person/people', I also support the notion of 'person first' language. Hence, I have decided to use 'person with disability' or PWD in this thesis to conform with the standards of Australia, where I undertook this study. I have, however, understood and have respect for the preference for using either term.

1.5.3. Social Inclusion

This thesis defines social inclusion as not being excluded from mainstream society. It reflects the notion of ensuring equal participation of all people in a community and their ability to exercise their rights of citizenship without any discrimination based on any kind of distinction such as disability, social and economic status, age, race/ethnicity, or gender.

This definition is adapted from those presented by several authors, such as Mulvihill, Cotton and Gyaben (2003), who state that 'the spirit of inclusion reflects the idea that everyone should have the opportunity to fully participate in all aspects of our society' (p. 62). In addition, Diez (2010) summarises that 'inclusion in society can be seen as a way of life, a unique approach to acting and participating in society, of perceiving others' (p. 165). Finally, the definition used in this thesis is adapted from Wright and Stickley (2012), who conclude that social inclusion is an intrinsic concept which has historically been linked to politics and policy, poverty, education and PWD, as well as those with mental health problems (pp. 1 & 9).

1.6. Outline of the thesis

This thesis is organised into seven chapters. Chapter One serves as the introduction and presents the background of the study, the topic statement, the research questions and objectives, the research approach and methods, the significance of the study, the key terminology used in this study, and an outline of the thesis.

Chapter Two presents the literature review to provide the main conceptualisations of disability and their implications for disability awareness. The chapter includes a discussion on understandings of disability, which covers descriptions of the three dominant models of disability, then ableism, rights and disability, citizenship, social inclusion, and United Nations' initiatives on the issue of disability worldwide. This is followed by a description of the social semiotics of disability, the representation of disability in the media, disability awareness and disability awareness videos. Due to the fact that this study focusses on Indonesian PWD and research was carried out in Indonesia, this chapter also includes a description of disability issues in Indonesia, which covers issues related to policy, statistics, definitions, cultural awareness and disability awareness in Indonesia.

Chapter Three is organised into two sections, research methodology, and research methods. The research methodology section begins with a justification for the use of PAR. This section then describes the origins of PAR - its meaning, purposes and characteristics, challenges and critiques, and the degree of participation in PAR, and ends with reviews of previous scholarly studies relating to the application of PAR. The research methods section covers the details of this particular study. It includes description of the research sampling, the data collection methods, the method of data analysis, a discussion of the rigour, and concludes with a description of ethical issues related to this study.

Following the chapter on research methodology, the research process is explained in Chapter Four. This chapter describes how the study employed PAR's dominant characteristic of cyclical processes. The four stages of observing, reflecting, planning, and acting were repeated three times as part of PAR's cyclical processes in this study. Therefore, this chapter consists of descriptions of PAR stages and its unique implementation in this study. This is followed by a description of the research process, which is organised under three headings: Cycles one, two, and three, with sub-sections on PAR's four stages in each cycle.

Chapter Five discusses the research findings and explains the research results in relation to the three objectives of the study. The description of findings on the first objective begins with the CRG participants' profiles, which illustrate the realities of the problematic life experiences of PWD in Indonesia. It covers five aspects: the difficulty of being accepted and included in their respective communities; the difficulty of having meaningful interpersonal relationships with others; the difficulties associated with gaining mobility access; the difficulty of obtaining opportunities for and access to education; and the difficulties associated with opportunities for and access to employment. This section is then followed by a description of the negative realities of Indonesian PWD. Findings related to objective two include the goal of positive disability awareness for Indonesia, and the concept of disability awareness, which consists of five components: the role of diversity, and the needs, rights, capabilities, and contribution of PWDs. The findings related to objective three include insights into the process of developing a disability awareness-raising strategy such as the one proposed and emphasised in this study.

In Chapter Six, I present a discussion of my interpretation of the study's results. The discussion is presented based on the three research objectives and then integrated with the literature. The discussion on objective one describes the realities of PWD's lives in Indonesia with regard to five subjects: barriers, ableism, the model of disability, the model of disability in Indonesia and cultural issues, and PAR. The discussion on objective two presents the key issues linked to three matters: the conceptualisation of disability awareness and disability awareness-raising; existing disability awareness initiatives in Indonesia, and existing disability awareness audio-visual media in Indonesia. The discussion on objective three delineates the disability awareness-raising strategies proposed by the research participants to cover three topics: the social semiotics of disability; the degree of participant involvement in PAR with video, and finally, the video-making and PAR process.

Chapter Seven outlines the conclusions and key outcomes drawn from the research findings. There are six main outcomes: the conceptualisation of disability awareness, disability awareness-raising and a disability awareness

video; the development of a disability awareness video; the PAR process and the video-making process; valuable lessons learned from employing PAR; the challenges in performing PAR; and finally, engagement with Indonesian people with disabilities. Chapter Seven concludes with a description of the limitations of the study, suggestions for future research, and possible recommendations drawn from the findings of the study.

CHAPTER TWO

LITERATURE REVIEW

This chapter begins with a restatement that this study is driven by the main research question: in what ways can awareness-raising strategies be used to increase the understanding of people with disabilities (PWD) as active members of the Indonesian society? This question is complemented by three key sub-questions: (1) What are the realities of an Indonesian PWD's life in Indonesia? (2) What is the state of current disability awareness in Indonesia? (3) What are the research participants' thoughts and ideas on the development of disability awareness-raising strategies in an Indonesian context?

Accordingly, this study has three objectives, based on these research questions. The first was to describe and analyse the realities of PWD life in Indonesia. The second was to explore and analyse the key issues related to the current disability awareness in Indonesia. The final objective was to develop disability awareness raising strategy, as proposed by the research participants. In order to address those objectives, I collaborated with Indonesian PWD in a Participatory Action Research (PAR) project.

This chapter reviews the recent literature to provide several bodies of scholarly work and a number themes relevant and significant to the study. It consists of a discussion of understandings of disability, which covered descriptions of the three dominant models of disability, ableism, rights and disability, citizenship and social inclusion. It also covers United Nations' initiatives on disability. This chapter also includes a description of the social semiotics of disability, the representation of disability in the media, disability awareness and disability awareness videos. Finally, the chapter embraces a description of disability issues in Indonesia, which include issues related to policy, statistics, definitions, cultural issues and disability awareness. Setting the context about disability in Indonesia was important as part of PAR process.

2.1 Understandings of Disability

The review of the literature in this section is mostly based on Western academic sources, primarily from the United States (US) and Western Europe. This is due to the fact that literature about the history of perspectives on disability in non-Western contexts is difficult to locate via online searches in existing academic library databases. This seems to be linked to the fact that very little non-Western documentation on disability, especially in Indonesia, reaches the academic community at the international level or in international publications. Non Western literature found in the search examines topics such as disability perspectives in Thailand (Naemiratch & Manderson, 2009); disability perspectives in India (Buckingham, 2011); disability perspectives among Indian PWD who live in the USA (Gupta, 2011); and studies focused on disability perspectives in Africa such as: Ghana, (Naami & Hayashi, 2012); Uganda, Africa (Katsui, 2008; Katsui & Kumpuyuori, 2008); Zambia (Katsui & Koistinen, 2008); and in South Africa (Heap, Lorenzo, Thomas, 2009).

Like many of these countries, Indonesia experienced colonialism from Western nations for hundreds of years and continues to be influenced by western nations although Indonesia has political independence. This has had a significant influence on the perspectives of disability in Indonesia, as described in Section 2.4. (Disability issues in Indonesia). Therefore, discussions in this chapter are important to position this research as an original contribution, addressing the need to develop non-Western documentation of disability experiences as this is a largely unexplored aspect of disability research.

2.1.1. Perspectives (Models) of disability

Disability and people with disabilities have existed throughout history and across cultures, and there is archaeological evidence of this in prehistoric times (Rothman, 2003 p.2). Over this long historical period, there have been various perspectives of disability that have been used worldwide. These perspectives are more commonly referred to as models or paradigms, terms

which some authors have used interchangeably. Other authors distinguish between the two where models are largely descriptive frameworks and paradigms refer to epistemological and theoretical explanations (Kuhn as cited in Oliver, Sapey, & Thomas, 2012, p. 14). This thesis refers to the meanings, perspectives or models of disability as the ways in which people think, perceive, interpret, and approach disability and PWD; and are the source of people's attitudes and behaviours (Shapiro, 2000, p. 88). General agreement can be found among key scholars (for example, Oliver, 1996; Rothman, 2003; Shapiro, 2000) that the major models of disability are the Moral/Charity Model, the Medical Model and the Social Model. This section will describe the first two models while the Social Model of disability will be described in the next section.

- The Moral/Charity Model

Culturally and historically, disability has generally been viewed as a form of disadvantage or misfortune, and PWD are viewed as victims of disadvantage or misfortune who are not desirable and are not accepted as a part of the community. History has also shown that this view generally triggers negative thoughts and attitudes of society toward persons who look or are perceived as being different from what is considered to be culturally normative (Rothman, 2003, pp. 4-7). Some dysfunction or anomaly in their body is viewed as "a sign of the moral status of the people, or ... a sign of divine favour or disfavour" (Couser, 2009, p. 1).

The moral model views and groups PWD according to such 'disfavour' characteristics that distinguish them from others, which become a negative label or stigma. "A stigma is a sign or mark upon a body of a person that reveals something bad, unusual or hidden about the person...and also a state of condition of disgrace or discreditation" (Rothman, 2003, p.15). It was evident that these marked differences resulted in keeping such people separate and divided from other people. This othering of people with disabilities set up a binary where they were considered 'lesser than' those without apparent disabilities. Based on this negative division, in ancient Greece and Rome, PWD were placed in the countryside and had to support themselves either by

begging or by being dependent on the mercy of relatives to care for them (Barnes & Mercer, 2010, p.1 5; Rothman, 2003, p. 4). They were devalued and ridiculed. This established prejudice, created connections to negative behaviours of the remainder of the community resulting in discrimination (Shapiro, 2000, p. 124) and social exclusion (Stool, 2011).

Historically disability was problematized and individuals then experienced stigma and discrimination. Disability was then problem of the individuals, as PWD were avoided or ostracized. This social avoidance or exclusion happens because their stigmatised difference raises a deep fear of contagion, or because their differences are reminiscent of something not desirable for the survival of generations. In this way, PWD are considered to be socially devalued (Wolfensberger, 1983) and therefore not worthy to be included in the mainstream of society.

The role of religions in explanations and perspectives on disability is also historically important because of its significant influence over populations/ nations. The role of religions included shaping moral thought, this included the belief that God was the source of health and all illnesses, including disabilities. There are two dominant streams of thought, existing side by side and simultaneously that have influenced much of our thinking today: first, disability is caused by God as a punishment for wrongdoing or sin and also as education about the power of the Almighty; and second, disability is created to foster obligation in others to care for people (Rothman, 2003, p. 5).

These moral thoughts have underpinned the closeness of the moral model and the charity model. The moral model is about why an individual has a disability, and views disability as a punishment from God for sins or wrongdoing by an individual, their parents or ancestors. Meanwhile, the charity model is about how individuals with disability are treated, and perceives PWD as victims of disadvantage or misfortune who deserve pity, and are objects of charitable giving by those who have no differences in their bodies or whose bodies are considered 'normal'. This model is based on altruism or philanthropy derived

from religion, which have influenced people's morals throughout history (Rothman, 2003, p. 5).

Both moral model and charity model locate disability's problems within the individual, due to their lack of a fully functioning body or mind which is also referred to as impairment. The models lead to ostracism, which often occurs due to the stigmatisation of individuals who are impaired, to be seen as inferior and to be avoided. Consequently, it also results in self-internalisation by people with impairment as being inferior and dependent (Edwards, 2009, p. 33; Smart & Smart, 2007, p. 91).

Although this is taken from the history of Western society, similar beliefs were also found among Hindus living in the US (Gupta, 2011), Hindus living in India (Buckingham, 2011), and Buddhists in Thailand (Naemiratch & Manderson, 2009) These researchers reported that Hindus and Buddhists also have the belief that disability is caused by God as a punishment for wrongdoing in the past life of people of disabilities and/or their families.

- The medical model

This model has developed and continued over time supported by the advancement of science and medicine. As with earlier views associated with religious teachings, this model sees the problem of disability as located within the individual (Hiranandani, 2005b; UN ESCAP, 2010), due to it is caused by fixed medical characteristics called impairments, which are regarded as abnormal (Smith, 2009 p. 22).

Thus, in the medical model, impairment is a biomedical phenomenon where an individual lack some vital elements or functions which result in long-term sickness, restriction and incapacity. This model is associated with 'the sick role', where individuals with impairments in certain physical, intellectual, psychological and/or mental conditions are excused from social obligations, but must willingly comply with the treatment and instructions of a professional to recover (Pfeiffer, 2005, pp. 26-27).

This model proliferated during the Middle Ages, where religious groups established hospitals for people in need (Brenton, as cited in Katsui, 2008, p. 11). Hospitals and medical schools were often built near monasteries, and the religious provided care for sick and disabled people (Castiglioni, as cited in Rothman, 2003, p. 5). Such traditions have continued into contemporary times where there are still hospitals and other services catering for 'the sick who are in need'. There is also an expectation that PWD or the person in the sick role is grateful and deserving of treatment.

The medical model has become a framework of thought and action throughout most of recorded history (Rothman, 2003), as well as the major perspective on disability (Hayashi, 2005, p. 46; Smart & Smart, 2007, p. 77), where people with disabilities are regarded as being in need of medical diagnosis, medication, and treatments by medical/health professionals to rehabilitate their functional loss due to impairments. This is seen today in examples where people who receive treatment following injuries or that acquire disabilities are expected to exhaust and comply with all forms of treatment to reduce their impairment.

The medical model is underpinned by personal tragedy theory of disability, which indicates that disability is a horrific event that happens randomly to unfortunate individuals (Oliver, 1996). According to Hiranandani (2005a), personal tragedy suggests that disability is 'a natural disadvantage suffered by disabled individuals when placed in a competitive social situation' (p. 72). It generates a way of thinking that mostly focuses on the individual's deviations from normative expectations in both physical and biological constructions and functionality. Thus, the model view PWD as not having the same value as average people; as 'others' and existing outside mainstream society. The model also results in the development of rehabilitation units, nursing homes, workshop centres and special education systems for PWD, which are segregated from mainstream institutions (Pfeiffer, 2005, pp. 27-31, Zastrow, 2004, pp. 539-541). It is commonly referred to as an 'out of sight-out of mind' approach (Rothman, 2003).

The next section outline the underpinning claim that disability should not be understood merely as an individual misfortune or medical experience, but as a socially constructed fact.

2.1.2 The Social Model of Disability

The theoretical reasoning of the social model of disability is social constructionism. Social Constructionism is commonly defined as an epistemological principle and approach based on a sociological theory on knowledge developed by Berger & Luckmann (1966) who argued that knowledge is socially constructed rather than being objective. This approach views knowledge as created by the interactions of individuals within society, and “is not something people possess in their head but rather something people do together” (Gergen, 1985, p. 270). Hence, social constructionism goes against the positivistic belief that knowledge and reality exist objectively.

Social constructionism places emphasis on everyday interactions between people and how they use language to construct their reality. It regards the social practices people engage in as the focus of inquiry (Andrew, 2012, p. 5). Accordingly, this approach describes knowledge and reality as constructed through interaction and conversation; and views social phenomena as the result of human interpretation. Thus, the Social Model of Disability consider disability as a social construction as it is “the result of human interpretation owing its existence to the beliefs and practices built around how any given society responds to human difference” (Gallagher, 2004, p. 1).

The description of the Social Model of Disability in this section is organised into three sections: (1) its development, (2) its purpose and characteristics, and finally, (3) its connection with research.

2.1.2.1 Development of the Social Model of Disability

This section will provide a brief overview of the historical development of the Social Model of disability based on the work of several notable authors in this field. The model emerged from discourse within the Union of Physically Impaired Against Segregation (UPIAS), which was established as an organisation of people with disabilities in the UK in 1976 by Paul Hunt, an activist with a disability, and Vic Finkelstein, a scholar with a disability. UPIAS contributed to the development of the British disability movement and disability studies in Britain (Oliver, 1996; Hayashi, 2005; Pfeiffer, 2005; Barnes & Mercer, 2010; Shakespeare, 2006). The key theme of this model is the influence of people with disabilities themselves and the model's development and articulation is a reaction to the dominant views and treatment of people with disabilities. There is consensus in the literature that these key themes contrast with other models explaining disability - models that were developed by scholars without disabilities (Pfeiffer, 2005; Hiranandani, 2005).

As discussed earlier, from a cultural and historical perspective, disability is generally perceived as an individual problem caused by illness and impairment. It occurs randomly to unfortunate individuals, and then brings suffering and social disadvantage. People with disabilities have been referred to as "others", and are deemed to be different from the culturally normative, and incapable of participating and contributing to their community. Consequently, these dominant images have created extraordinarily negative public attitudes, discriminative policies, and segregated services and programmes. For that reason, UPIAS was formed with the aim of replacing "segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their own lives" (Shakespeare, 2006, p. 197). UPIAS argued that people with physical impairment have been disabled by their society, and as a result they have become an oppressed group in society (Oliver, 1996, p. 33). To support this argument, UPIAS provided the following definitions of impairment and disability:

Impairment is lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body.

Disability is the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities (Oliver, 1996, p. 33).

In the 1980s, the original UPIAS ideas were further elaborated on by Mike Oliver, a scholar with disability, who then encapsulated them in terms of the Social Model of Disability. It was a new articulation in viewing disability (Thomas, 2004, p. 571; Shakespeare, 2006, p. 197). Based on a social model, Oliver (1996) delivered disability as:

All the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society (p. 33).

The Social Model was accepted and discussed enthusiastically by PWD who learned and concluded that it has a timely connection with their own experience of oppression. However, this model is a contested, as it has been debated from 'insiders', PWD themselves, and from the outside by people without disabilities. From the inside, scholars with disabilities such as Jenny Morris, Liz Crow, Sally French, and Carol Thomas have argued that this model has a tendency to neglect the personal experience of impairment, which can be misinterpreted to be assume that there is a universal experience among the disabled (Swain & French, 2000, p. 571; Shakespeare, 2006, p. 202; Barnes & Mercer, 2010). In addition, this model indicates problematic consequences such as for some people with impairment who self-define as disabled and feel alienated from other disabled people because they are not considered

disabled (Humphrey, 2000, p. 66) or “not disabled enough” (Pfeiffer, 2005, p. 29). From an outsider’s point of view, this model has been criticised by medical sociologists, policy researchers, policy makers, and service providers, who have insisted on the causality of disability with impairment and illness, that disability was caused solely by illness and that impairments are interpreted as personal medical tragedies (Oliver, 1996; Barnes & Mercer, 2010; Shakespeare & Watson, 1997).

These critiques have been well-counteracted with the explanation that this model does not deny the reality of pain, chronic illness, and impairment experienced by PWD, nor that it may have disabling consequences. The model emerged to counter the dominant model which assumes a causal link among those aspects and defined disability as an individual problem that solely belongs to people with illness and impairment. The model argues that the problem is not caused by individual limitations. Disability is caused by “society’s failures to provide appropriate service and adequately ensure that needs of disabled people are fully taken into account in its social organisation” (Oliver, 1999, p. 32). Thus, disability is a social problem and “a long-term social state is not treatable medically and is certainly not curable” (Oliver, 1999, pp. 35-36). For this reason, this model focuses on the economic, environmental and cultural barriers encountered by people perceived as having some form of physical, mental or intellectual impairment (Barnes & Mercer, 2010, p. 30). In addition, Carol Thomas wrote the following supportive description to clarify some key aspects of these debates:

Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing. This means that it is entirely possible to acknowledge that impairments and chronic illness directly cause some restrictions of activity—but such non-socially imposed restrictions of activity do not constitute ‘disability’. Such non-socially imposed restrictions might be better captured by the concept ‘impairment effects’ (Thomas, 2004, pp. 580-582).

The Social Model of disability, according to Oliver (1996), is not a social theory but is a way of understanding how the world treats people with disabilities, which leads to them becoming disadvantaged. This model serves as an intellectual expression to challenge the dominant individual medical model of disability and ableism (Hughes & Paterson, 1997). In other words, this model was intended as an instrumental tool of the British disability movement in their campaigns against various forms of discrimination towards people with physical, mental or intellectual impairment (Shakespeare, 2006).

Indeed, the Social Model of disability emerged as a reminder of the need to be cautious of the over-medicalisation of the problems and issues that revolve around disabilities. Medicalisation is related to the medical aspects of disability (Oliver, 1996), which means that this model acknowledges that many disabled people have illnesses at various points in their lives, which need medical treatment by medical professionals in medical institutions. However, over-medicalisation occurs when the problem of disability is reduced to its medical aspects, assuming that all disability-related problems can be solved by medical knowledge and treatment, and that medical professionals know best how to solve the problem of disability (Oliver, 1996; Bricher, 2000). In the reality this can mean overlooking the need for changes to attitudes and environment as the focus is solely on the individual who is 'disabled'.

Medical professionals are socialised by their own training to believe that they are 'experts' and are accorded that role by society. Based on their expertise, disability is reduced to being merely the individual's functional limitations due to illness and/or impairment, and their only 'aim [is] to restore the disabled individuals to a state that is as near normality as possible' (Oliver, 1996, p. 37). Over-medicalisation is seen to legitimise 'experts' as the decision-makers regarding the lives of PWD. It is inappropriate and, at worst, oppressive to people with disabilities because they are regarded as inferior and dependent, while the experts are viewed as superior, powerful, and dominant. The Social Model of disability has pointed out the ways in which non-disabled experts can

have a harmful influence on the everyday lives of PWD, and it focuses more on creating changes in their living conditions (Barnes & Mercer, 2010, p. 31)

Finally, other supporters of the Social Model have explained that the model does not deny that there are benefits of, and a necessity for medical and rehabilitation services and support for PWD. This importance of medical intervention, professional support, and the availability of technical aids that alleviate impairments, as well as the promotion of the autonomy and equality of PWD are acknowledge as important to PWD living a fulfilling life (Parnes *et al.*, 2009; UNESCAP, 2010). This model argues that it is important to determine 'which aspects of disabled peoples' lives need medical or therapeutic interventions, which aspects require policy developments, and which require political action' (Oliver, 1995 cited by Hughes and Paterson, 1997, p. 330).

Thus, the development of the Social Model of disability can be summarised as follows: First, this model has been developed and articulated by PWD themselves, mainly activists and academics with disabilities in Britain; second, this model was derived from the British disability movement, which was inspired by the civil rights movement in the 1960s to challenge the historical oppression and exclusion of disabled people in Britain around the 1970s; and third, this model emerged from intellectual and political arguments that reject the causal link between disadvantage and biological functional limitations, and the over-medicalisation of problems and issues of disability.

2.1.2.2 Purposes and characteristic of the Social Model

The Social Model was developed as a paradigm shift breaking from the dominant view of the personal tragedy theory of disability. Therefore, the initial purpose of the Social Model was to be a practical or instrumental tool of the British disability movement in their campaigns against various forms of discrimination toward people with disabilities (Oliver, 2013). Specifically, it means that this model aimed to explore, on a pragmatic level, what can be

done to change the environmental barriers and social attitudes that restrict many people with certain physical, mental or intellectual conditions from enjoying life in the same way as other people do in their society.

Several key theorists in the field have argued that, according to the Social Model:

- The characteristics of disability are a natural part of the human experience. It can happen randomly to anybody, anywhere, and at any time in any life episode.
- Disability is viewed in a continuum between ability and disability.
- Disability is a societal problem due to social practices based on ableism, which place social restrictions on and cause the exclusion of PWD.
- The problem of disability is located within society, not in PWD; therefore, the focus of attention is to eliminate and/or remove the attitudinal and institutional barriers causing the social restrictions and exclusion of PWD.
- Disability is not a personal medical tragedy which is equated with a loss of potential, productivity and social contribution.
- PWD are to be viewed as citizens who have the same rights as people without disabilities.
- PWD deserve welcoming and respectful attitudes. (Hayashi, 2005, p. 47, Rothman, 2003; Oliver, 2013; UNESCAP, 2010, p. 5).

2.1.2.3 The Social Model and research

The emergence of the Social Model of Disability is closely related to the demand from the disabled rights movement to shift the research agenda. Historically, disabled people have been the subject of voluminous medical experiments and research, which mostly focused on functional limitations or the consequences of impairment (Bricher, 2000; Valade, 2004; Barnes & Mercer, 2010). However, this research has been criticised by Kitchin (2000) – a scholar with disability: “

One of the most annoying things that all these research, where does it actually lead in the long term? And what use is it put to... A lot of it is written in such a way that it is very academic. I have problems with some of the academic work as I don't think it relates really to the what life is like for people on the ground. (p. 29)

Another scholar has argued that "disability is not measles. It is not a medical condition that needs to be eliminated from the population" (Rioux, 1994, p. 7).

The Social Model of Disability reinforces the research shift from individual-medical problems based on the positivistic paradigm to the social and environmental barriers experienced by disabled people. The research must state that the outcomes must be relevant to the lives of PWD, and that active participation of PWD in the research must occur (Pfeiffer, 2004, p. 40).

Therefore, this model also advocates for the important role of people with disabilities in research, and an acknowledgement of the lived experience of people with disabilities as a source of knowledge (Hergenrather & Rhodes, 2002, p. 60; Ishak, 2013, p. 125). Therefore, this model is closely connected to the ideas underpinning the approach of participatory action research/PAR (Bricher, 2000; Barnes & Mercer, 2010). PAR will be described further in the Chapter Three.

2.1.3 Ableism – Disabling Societies

Worldwide, throughout history and across cultures, PWD have faced prejudice and discrimination due to the way other people view and react to them. This discrimination is one means of social exclusion. Another form of social exclusion and separation from mainstream society was PWD being forced to live in segregated special units, to attend segregated special education facilities, to struggle with inaccessible public transportation and buildings, and facing problems and discrimination gaining employment (Pfeiffer, 2005, pp. 31-34). Some forms of discrimination and exclusion may be overt and others may

be less obvious. For example, a research project with PWD who were members of one of the disabled peoples organisations (DPO) in Melbourne, Australia found: “even in an organisation that is specifically attuned to meeting the needs of disabled people, there is still considerable exclusion and institutional discrimination” (Radermacher, Sonn, Keys & Duckett, 2010, p. 333).

Thus, PWD are discriminated against in the same ways, just as discrimination occurs on the basis of culture and race (racism), and gender (sexism). Racism and sexism have been spoken about and described for many decades, however, the description of experiencing ‘ableism’ is still rarely acknowledged. Ableism is less widely used or referred to, due to its more recent emergence as an academic and ideological concept used primarily within academia. Ableism is also a description of a social categorisation and discourse, representing more than a model.

Ableism is defined as “discrimination in favour of the able-bodied which includes the idea that a person’s abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to non-disabled people” (Linton, 2006, p. 161). Ableism is the result of false beliefs and attitudes toward PWD. Ableism is concerned with how able bodiedness and able bodied individuals experience privilege relative to individuals with disabilities. For example, they are not excluded from social and economic participation due to the nature of the environment or social expectations.

Ableism is also referred to as ‘disablism’. The use of the terms ableism and disablism appear to be used interchangeably, dependent on an author’s personal preference, or on their different foci of interest (Radermacher, 2006). Radermacher’s preference is for the use of ableism as a way to understand the impact of such discrimination towards PWD (p. 17). In her study with 12 participants (six PWD who were active board members, two PWD who were staff and four non-disabled staff of the DPO), Radermacher illustrates how ableism was expressed in a number of ways. First, she discovered from the

participants' comments that the expectations of the capabilities of PWD are low. Secondly, through analysing the comments of participants in the study, she found that ableism also degrades the ability and worth of people with visual impairments. Thirdly, in her expectation as an able-bodied researcher that the impairment of her disabled participants presents the greatest obstacle, which in turn prevents participation (Radermacher, 2006, p. 102).

The most important point is that terms, ableism and disablism, are concerned with the social practices, designs, and organisations which are developed and reproduced based on the perspectives of the able-bodied or people without disabilities. This ultimately prevents or limits PWD from fully participating in their communities and society more widely. Ableism is "a concept that is useful in explaining disabled people's experience of oppression and constructions of disabled identity because it focuses on the contours of the non-disabled perspective" (Loja, Costa, Hughes & Menezes, 2013, p. 200).

Thus, PWD experiences the range and types of oppression and discrimination through every day social practices, designs, and organizations which are significantly influenced by how disability is understood and conceptualised. In examining how ableism operates in the lives of PWD, it is important to understand how organisations intended to redress discrimination operate in this policy domain. The next section outlines the emerging claim that disability should be understood as a societal-not individual-phenomenon and a human rights issue where individuals can live free of discrimination and exclusion.

2.2 Rights and disability

2.2.1 Rights movements and Disability movements

Rights movements and human rights discourse emerged after the Second World War. This period triggered independence and civil rights movements in most parts of the world. These movements were based on the social justice perspective as a response to the oppressive and exploitative conditions experienced by people from certain races or groups around the world. Before this period, there was a general agreement that human rights were a "domestic

issue of sovereign states and the principal duty of other nations were to not interfere” (Ollerton & Horsfall, 2013, p. 617).

These right movements became emerging when the United Nations (UN) was established in 1945, and the UN released several pieces of international human rights legislation which affirmed fundamental human rights for all people around the world (United Nation, 2009). The Universal Declaration of Human Rights in 1948, the Declaration on the Rights of mentally retarded persons in 1971, and the Declaration on the rights of disabled persons in 1975 (Millward, Ojwang, Carter, & Hartley, 2005, p.154), were all critical historical moments in advocating for equal treatment and non-discriminatory treatment of individuals.

As described earlier, throughout history and across cultures, PWD have experienced discrimination due to ableism and social devaluation (Wolfensberger, 1992). This exclusion means that they were not valued socially as much as other people without disabilities and that they did not often experience dignity, autonomy, respect, supportive relationships and participation in the social activities of their respective society. In other words, the rights of PWD were ignored and violated. The dominant socio-historical perceptions about disability have attracted growing criticism from emerging organisations of disabled people and disability activists (Mercer, 2002, pp. 118-130). This is in addition to the growing impetus to see disability as a human rights issue and not merely as an individual problem related to illness or a lacking part of the body or mind, nor solely defined in medical terms.

Encouraged by civil rights movements against any form of discrimination worldwide, disability rights movements have been led by disabled people and disability activists in the US and the United Kingdom (UK) to fight against the oppressive and exploitative conditions experienced by people with disabilities due to ableism. The assumptions of an able-bodied rights-bearer which underpinned the Universal Declaration of the United Nations can inform discriminatory practices toward PWD, as it espouses formal equality that does

not recognise diversity in relation to a person's identity, including someone with a disability (Ollerton & Horsfall, 2013, p. 618). Equal treatment does not necessarily mean identical treatment. Thus, although this declaration details the minimum conditions for human beings to live a dignified life and forms a common vision for the international community, it has made little impact on the lives of the world's PWD due to its traditional human rights paradigm, which is based upon ableist assumptions (Ollerton & Horsfall, 2013, p. 617).

Therefore, the disability rights movements fight for equal rights and opportunities to combat the social exclusion and oppression experienced by PWD. Research has indicated the civil rights and social justice perspective (Lutz & Bowers, 2007, p. 11) has been asserted as the reason for the claim that PWD are oppressed. They are oppressed because they are viewed as different, are perceived as abnormal, not equal to others, and are kept at a physical and social distance by people without disabilities. They imposed by dichotomous views on ability versus disability, between 'we' (without impairment; able-bodied) and 'they' (individuals with impairment). As a result, they are discriminated against in most aspects of their lives due to their physical and/or mental impairments, and ableism creates barriers for them.

PWD are rights holders who have the same rights as all citizen without disabilities. They are entitled to the rights of a life with dignity and respect, and a 'normal' social life. This includes the opportunity to have meaningful relationships with others, the opportunity for marriage, parenthood, social status, education, employment, and so on. Therefore, equal rights and equal opportunity are central issues. Equal does not mean identical, but means the ability to acquire reasonable protections and support so that PWD can enjoy the same rights as other people without disabilities. For that reason, as bearers of these rights, PWD are entitled to advocate for the removal of institutional, physical, informational, social and attitudinal barriers that prevent them from participating fully in society. They do not want legislators and policy makers to identify their needs for them in the same way that traditional providers of care have done in the past because it displays inequality and inequity.

2.2.2 Citizenship and social inclusion

The early United Nations declarations largely assumed that it was the responsibility of member states to ensure rights were upheld. In this way the states had responsibilities and obligations to their citizenry.

The term citizenship is initially defined as a national identity that has inherent rights and responsibilities. Many people are assumed to possess the citizenship of a given state if they were born in that country. In fact, “citizenship is a status bestowed on those who are full members of a community” (Marshall, 2009, p. 149).

Citizenship has various dimensions. T.H Marshall described three forms of citizenship namely civil, political and social citizenship (2009, p. 149) as elements of the same process of broadening citizenship concepts.

Civil citizenship correspond to the entitlement to basic rights, such as freedom to speech, thought and faith, and the rights to own property;

Political citizenship implies the right to vote for office holders, or as to be a candidate oneself for elected position of power.

Social citizenship defined as the right to live the life of a civilized being according to the standards prevailing in the society. (Marshall as cited in Hooghe & Oser, 2015, p. 5).

Furthermore, Marshall’s form of citizenship augmented the belief that social coverage must be universal, include all members of society (Hooghe & Oser, 2015, p. 6), and that citizenship is a principle of equality (Marshall, 2009, p. 150). This means that citizenship closely related with social inclusion.

In a disability context, citizenship is about what it means for PWD to be fully participating members of the society in everyday life (Yeung, Passmore & Packer, 2008, p. 65). Moreover, the social model of disability suggests three dimensions of citizenship approach which includes:

- disabled people are seen as contributing members of society as both workers and valued customers (users);
- disabled people are recognised as empowered individuals (voters);
- disabled people are seen as active citizens with all that implies in terms of rights and responsibilities (Oliver, Sapey, & Thomas, 2012, p. 23.)

However, the reality experienced by PWD is often contrary to the social model and Marshall's dimensions of citizenship. The enactment of their citizenship is still ignored by their community members and excluded from mainstream society. This social exclusion happens as a result of ableism and the confluence of two false beliefs which still exist in today's society. These false beliefs are that PWD are incapable of making a significant contribution to the community, and that they are somehow not of the same value as other citizens without disabilities (National People with Disabilities and Carers Council, 2009, p. 11; Ollerton & Horsfall, 2013, p. 617).

In regard to ableism, Wiman (2003) asserts that PWD often encounter denial of their citizenship "while trying to participate in mainstream society which has been designed with non-disabled people in mind" (p. 15). This means that ableism has led to the denial of citizenship of PWD in mainstream society and overlooking the role of the state to ensure their active citizenship, while their fundamental needs are the same as those without disabilities. Moreover, they are an inherent part of mainstream society and their population is large throughout the world estimated at between 15.6 and 19.4% of the global population in the 2010 (WHO 2011, p. 261). Consequently, one-fifth of the world's population are PWD. In this way, PWD represent the world's largest minority but are amongst the most marginalised in every society (Parnes, et.al, 2009, p. 1177). This has been expressed by the WHO (2011):

It will be hard to improve the lives of the most disadvantaged people in the world without addressing the specific needs of persons with disabilities. People with disabilities need to be included in development

efforts, both as beneficiaries and in the design, implementation, and monitoring of interventions (pp. 12-13).

Unfortunately, practical development efforts, according to the United Nations Commission on Human Rights, “often fail to recognise the rights, needs, and potentials of PWD; while they are often among the poorest of the poor, they have been excluded from mainstream development” (Wiman, 2003, p. 13).

The situation faced by PWD is much more difficult in developing countries, such as in many places in the Asia Pacific region, where it is estimated that, out of “400 million people with disability, over 40 % are living in poverty. Poverty and disability reinforce one another, contributing to increased vulnerability and exclusion” (United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP), 2002; WHO, 2011, p.10; Wiman, 2003, p. 28).

Disability and poverty are highly correlated. Poverty results in illiteracy, low income, and harmful living and working conditions, which escalates the risk of disability through malnutrition, bad sanitation, inferior health services and facilities. Additionally, the presence of a disability, “can trap people in a life of poverty because of the barriers they face to taking part in education, employment, social activities, and indeed all aspects of life” (Mont, 2007, p. 1). In summary, poor PWD experience double discriminations, based on their poverty and their disabilities. This in turn contributes to them being devalued and excluded from the activities of ‘normal citizenship (Smith, 2009, p. 22) in mainstream society (Mercer, 2002, p. 130).

2.2.3 United Nations initiatives

There have been some significant international initiatives in response to PWD issue worldwide. The United Nations declared the year 1981 as the UN International Year of Disabled Persons (IYDP) (United Nations, 2004) and the subsequent decade as the UN Decade of Disabled Persons 1983-1992

(United Nations, 2008). Since 1992, the UN has declared December 3 as the International Day of Disabled Persons (Wiman, 2003, p. 11). These international initiatives generate avenues to emphasise the world's concern and commitment to equal opportunity for PWD. In order to maintain attention on disability issues in some regions, Kuno (2007) explains that:

A number of regional Year of Disabled People and Decade of Disabled People were implemented: Asia and the Pacific (1993-2002, 2003-2012), Africa (2000-2009), the Middle East (2003-2012), and Latin America (2004). The ultimate aim of these initiatives was the realisation of "full participation and equal opportunity" for people with disabilities which was originally set as one of the aims in the IYDP (p. 10).

In 2002, UN ESCAP proclaimed the extension of the Asian and Pacific Decade of Disabled Persons - 1993-2002 - for another decade, 2003-2012. "The additional decade was needed in order to effectively promote and enact the idea of an inclusive, barrier-free and rights-based society for people with disabilities in the Asia Pacific region" (UN ESCAP, 2002, p.3). All countries in the Asia Pacific region - except Armenia, Azerbaijan, and Kazakhstan - "are signatories to the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region as well as two consecutive Asian and Pacific Decades of Disabled Persons (1993-2002 and 2003-2012)" (UN ESCAP, 2010, p. 17).

The latest achievement of these international initiatives is to emphasise the world's concern and commitment to equal opportunities for persons with disabilities. The publication of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) was the first legally binding convention of its kind. It was issued on 13 December 2006 at the United Nations' Headquarters in New York, and became fully operational in May, 2008 (UN ESCAP 2010, p.1). The purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (The CRPD,

2007, p. 5). It is argued that this convention confers no new rights to those outlined under the Universal Declaration, but it does provide a legally substantial resource through which rights can be claimed by disabled people (The CRPD, 2007; Stevenson, 2010; Ollerton & Horsfall, 2013).

The CRPD enables people with disabilities to enjoy the same rights as other people by:

- 'affirming and applying core human rights concepts, such as dignity, equality and the freedom to make one's own choices, to the situation of people with disabilities' (The CRPD, 2007, p. iv);
- 'minimising the adverse impacts of impairment; and
- eliminating discrimination and prejudice' (WHO, 2011, p. 13).

Additionally, Muir and Goldblatt (2011) assert that "living in and being included in the community is a key part of the CRPD (Article 19), making social inclusion and community living not only socially just, but also a legal right" (p. 630).

The CRPD was passed due to the recognition and realisation of the human rights of PWD as had happened with other disadvantaged groups previously (Stevenson, 2010). The rights of people with disabilities around the world are neglected since they continuously experience inequalities, are subject to violations of dignity, denied autonomy and denied a share of society's resources based on their unexpected 'differentness' (Pfeiffer, 2005, pp. 28-31; WHO, 2011, p. 9). According to the United Nations Treaty (2012) as of August 30, 2012, "153 countries had signed the CRPD, of those signatories 48 countries have not ratified it and 13 countries have not signed but have ratified it. There are 18 Asia Pacific countries amongst those signatories that have not ratified it" (pp. 1-3). Upon ratification, the states will be legally bound to implement the convention's obligation at the national level. The following actions need to be taken:

- modify or repeal laws, customs, or practices that discriminate directly or indirectly;

- include disability in all relevant policies and programmes;
- refrain from any act or practice inconsistent with the CRPD;
- take all appropriate measures to eliminate discrimination against persons with disabilities by any person, organisation, or private enterprise (WHO, 2011, p. 9)

Finally, countries ratifying the CRPD are required “to report this implementation regularly to a United Nation monitoring committee” (CRPD, 2007, p. iv). The CRPD’s signatories are required to include citizens with disabilities in any process of national development. All stakeholders worldwide are now legally obligated to actualise the human rights of PWD. The CRPD represents substantial transformation in global understanding and responses towards disability. In other words, the CRPD made PWD legally visible in their societies and at the international level (Ollerton & Horsfall, 2013, p. 619). It signifies that disability is part of the human condition, and not merely a medical problems of individuals who have an impairment. Moreover, it emphasised that PWD are citizens who have the same rights to be respected and assured as all citizens. The implications of the CRPD in detail for Indonesia will be described in Section 2.4.

The next section discusses representations of the media and disability, which is intended to provide an insight into the close and important relationship between the two concepts. Media can play an important role in influencing people’s views of disability and PWD. The media can shape people’s minds to conform with, or be contrary to the principles of the Social Model.

2.3 Media and disability

The term media ‘in a broad sense includes a means or agency for transmitting or producing an effect’ (Collins, 1997 as cited in Cocks, 2006, p. 7). What is commonly transmitted or communicated are words or language that include texts, sounds, and images. Thus, it includes forms of mass media such as

television, film, and printed/written media such as books, magazines, newspapers, bulletins, booklet, advertising billboards, posters and flyers.

The media have the power to shape people's assumptions, beliefs and practices toward people who are at risk of being accorded low social value, such as PWD (Cocks, 2006, p. 1; Shapiro, 2000, p. 13). Alternatively, they can raise awareness and dispel myths about PWD. The media, however often influences and reflects social values and practice through "the visual and verbal images alongside the tone of coverage and the way social objects are represented and framed define the salience of a phenomenon, influence public opinion, and shape and influence public policy, legislation and research" (Soffer, Rimmerman, Blanck, & Hill, 2010, p. 688).

Therefore, it is important to try to unpack the relationship between the media and disability, bearing in mind that the media also has an essential role in the process of social change and reform for PWD as groups of people who are disadvantaged, experience discrimination or who are at risk of this (Cocks, 2006. p. 2). As such, any mass media - print or electronic - and the rest of society, are responsible for removing barriers, especially those related to the insensitive attitudes of society, to the willingness to accept and respect PWD (Isaac, Raja, & Ramanan, 2010, p. 627-630).

In the following section, the relationship between the media and disability in this PAR project will be divided into four areas: the social semiotics of disability, the representation of disability in the media, disability awareness, and disability awareness videos.

2.3.1. The social semiotics of disability

The term social semiotics of disability has been used by Gary Woodill (1994) to provide a framework for researching "the meaning and origins of the words and images about disability that form part of the cultural codes we all take for granted and in which we are all immersed" (p. 204).

Woodil (1994) has described the social semiotics of disability as:

A power tool in the analysis of the situation and social construction of persons with disabilities. It shows us how signs of difference that are learned and used from an early age by people both with and without disabilities can create our conscious and unconscious images of what it means to be disabled, and how these representations can perpetuate oppression and helplessness (p. 219).

For this reason, the social semiotics of disability help us recognise and realise how words, language or images are used to construct understandings about how an individual with disability is portrayed in the world, and how these words, or images, often consciously and/or unconsciously over-represent or stigmatise an individual with disability.

The social semiotics of disability have been affected by Western culture. The way people define or understand and treat people with disabilities nowadays is not unaffected by the attitudes and beliefs imported from Western Europe and other areas of the world due to colonialism. Western culture highly values physical strength and adroitness (Rothman, 2003, p. 17), and having a beautiful body/figure and being physically attractive (Zastrow, 2004, p. 546). Beauty is often inaccurately identified with goodness, and ugliness is often portrayed as evil. Books, movies, and television have historically depicted protagonists to be physically attractive, whereas the villains have been portrayed as 'ugly', as horrible looking. Snow White, for example, was lovely, in contrast to the evil witch who was physically undesirable. Accordingly, children have been wrongly taught that being good-looking will lead to a good life, and being ugly or having unattractive features is a sign of inferiority. Furthermore, the emphasis on beautiful body/figure and being physically attractive, especially by the media, has resulted in society's false belief that an individual with disability "ought" to feel inferior, and consequently persons with disabilities are often pitied as being less fortunate and given sympathy" (Zastrow, 2004, p. 546). Zastrow named these facts as society's reactions to disabilities.

Zastrow's concept of society's reactions to disability also deeply reflected Woodil's concept of social semiotics of disability. Moreover, these facts also illustrated how the social semiotics of disability have been affected by Linton's concept of ableism (as described in section 2.1.3 - ableism) and the personal tragedy theory of disability (as described in section 2.1.1 - perspectives of disability).

The above-mentioned fact that society, especially children, have been wrongly taught by the media of the importance of being good-looking, having attractive features, and a beautiful body leads to the social construction of PWD are inferior and less fortunate than non-disabled people, are confirmed by relatively recent research. Research has revealed that people are not born with prejudice against PWD, but acquire and internalise this from adults, the media, and from how the society is organised (Beckett, 2009; Kirkwood & Hudnall, 2006). This means that the media, which refer to texts, sounds, and images transmitted via mass media such as television, film, and printed/written media such as books, magazines, newspapers, bulletins, booklets, advertising billboards, posters and flyers, have been contributing to prejudice against PWD. It also reflects the process whereby the media becomes a vehicle of the social semiotics of disability. The next section attempts to unpack the social semiotics of disability by describing the representation of PWD in the mass media.

2.3.2 The representation of disability in the media

The media plays a significant role "in influencing the way citizens look at disability, and...it can perpetuate stereotypes of disability through its portrayals of characters" (Ciot & Hove, 2010, p. 525). A number of researchers have identified the most common western media representation of disability and PWD, which are presented in Table 2.1

Table 2.1 Common representations of PWD in film and television

Longmore (1987)	Cumberbatch and Negrine (1992)	Nelson (2000)
PWD as evil criminals with no soul	as an object of fun or pity'	as a threat (evil and warped);
PWD as a monsters		as victim (telethon)
PWD as maladjusted		as unable to adjust
PWD as heroes		as a hero (supercrip)
PWD as asexual or sexually deviant	as an object of charity'.	as one to be cared for (a burden)
		as one who should not have survived.

Compiled from Ciot & Hove, 2010, p. 526; Saito & Ishiyama, 2005. p. 440; Schwartz, *et al*, 2010, p. 842)

Indeed, these representations reflect the stereotypes of PWD in film/movies and television. These also reflects the social semiotics of disability, which have been affected by ableism (as described in section 2.1.3 - ableism) and the moral and medical model of disability (as described in section 2.1.1 - perspectives of disability).

Moreover, representation of PWD and messages about disability are often not delivered by the PWD themselves, but from able-bodied people who are often celebrities, such as Christopher Reeve, Muhammed Ali (Schwartz *et al*, 2010, p. 847) and Al Pacino (Connor & Bejoian, 2006, p. 56). The use of celebrities "may drown out the voices of PWD" (Schwartz *et al*, 2010, p.848) due to the fact that they take on the role of, or speak for, PWD which often happens without approval from the PWD they are representing (Swain & French, 2000, p. 572). Thus, it often consciously and/or unconsciously over-represent or stigmatise PWD.

These negative facts were happened because the media's job in the business world is to capture an audience, to sell to advertisers. To do so, journalists, including media producers, writers, editors, directors, TV show creators and film/movie makers, work based on their own stereotypes and values because "stereotypes simplify life"... "there is little hope that the media will challenge

stereotypes” (Mitchell, 2008, pp. 24-25). The ableism among non-disabled people around the media business have taken these stereotypes for granted and feel no need to make further enquiry, exploration or research. This has much potential for mass media to present inaccurate information and representation of disability and/or PWD that is passed off as truth (Mitchell, 2008, p. 24). “All too often individuals with disabilities are inaccurately portrayed” (Schwartz *et al.*, 2010, p. 841).

Therefore, the stereotype-based media leads to the perpetuation of negative images and the misrepresentation of PWD. Ironically, this has been the case until relatively recently, and there has been “a dominance of disabling images across a range of modern media” (Barnes & Mercer, 2003, p. 109). A number of researchers (i.e. Krogh, 2010; Mitchell, 2008; Schwartz *et al.*, 2010) have conducted studies with reference to this negative representation in the mass media.

- Krogh’s study in Sweden aims to change the representation of PWD in the media in order to improve on the number of PWD portrayed and the way these persons are framed; from stereotypes as heroes or victims to multifaceted, real-life people. This study employed seminars and training sessions to open dialogue and cooperation between reporters/producers from the television company with media savvy PWD. This study achieved two results. First, there was an increase in the number of persons with disabilities who could appear in the media, either as producers of media content or as sources for expert commentary (preferably on issues other than disability as well). Second, there was a change in media personnels’ attitudes towards persons with disabilities so that they were treated as persons (‘like us’) with human rights and not as patients (‘like them’) (Krogh, 2010, p. 380).
- Schwartz’s study in the US reveals that when films were selected with criteria which considered the semiotics of disability, films successfully dispelled stereotypes and promoted disability equality. The study used selection criteria such as a film having to present a real PWD as an

actor/presenter and portraying realistic stories about normal life in the daily lives of individuals with disabilities (Schwartz *et al.*, 2010, p. 848).

- Mitchell's study in the US is to explain ways to use electronic media (such as movies) and print media (books) in classroom to teach about stereotypes related to PWD. The study created a media analysis form to help students to recognize/identify the stereotypes in the media and to consider their effects on the audience as well as real PWD. The study found that student assignment using the media analysis form and leading students through discussion is very helpful in shaping their future beliefs and actions concerning stereotype of PWD (Mitchell, 2008, pp. 24-29).

In sum, it is highly expected that any media-print, television, radio, and movie-makers recognise their social responsibility (Isaac *et al.*, 2010, p. 629).

The mass media is not merely a disseminator of information but a moral entrepreneur that is a powerful, active social agent that can defines the 'right' and the 'wrong'". This stresses the importance of the need to change the way disability is represented in the media (Soffer *et al.*, 2010, p. 696).

Accordingly, the representation of disability in the media are closely related with disability awareness. The next section highlights some important aspects of disability awareness.

2.3.3 Disability awareness

The discussion of disability awareness in this section includes its conceptualisation, how it is expressed, and its outcomes.

2.3.3.1 The conceptualisation of disability awareness

Raising awareness regarding PWD is one of the most important aspects of the CRPD. This is officially reinforced in Article 8, which stipulates the objectives and measures to achieve disability awareness, but it does not straightforwardly define disability awareness. This means that the CRPD not states an official

or formal definition of disability awareness. There are almost difficult to find any literature which specifically addressed the definition of disability awareness and its relation with the disability awareness-raising.

Furthermore, according to UN ESCAP (2002) disability awareness has not been thoroughly addressed especially in developing countries such as Asian and Pacific countries including Indonesia. Due to this, disability awareness became one of the strategic actions identified in the Asian and Pacific Decade of Disabled Persons-2003-2012 in order to achieve the inclusion of people with disabilities in all activities in the community (UN ESCAP, 2002).

With lack of reference to the concept of disability awareness and disability awareness-raising, this study proposes that disability awareness-raising may be defined as a process of information exchange through text and image about disability and PWD in order to improve mutual understanding between people with and without disabilities and to develop the competencies and skills necessary to enable changes in social attitudes and behaviour toward PWD.

The above-mentioned definition is inferred from the handbook written to provide guidelines on awareness-raising for the United Nations Literacy Decade 2003-2012. This handbook clearly defines awareness-raising as ‘a process which opens opportunities for information exchange in order to improve mutual understanding and to develop competencies and skills necessary to enable changes in social attitude and behaviour’ (Sayers, 2006, p. vii). By way of contrast, compiling from a number previous study, Columna, Arndt, Lieberman, Yang (2009) indicated that disability awareness often referred to “a positive attitude and increased empathy toward PWD” (p. 19).

2.3.3.2. The Outcomes and expressions of disability awareness

The outcome of disability awareness

The CRPD officially reinforced the outcome of disability awareness in Article 8 (1), which stipulates:

1. States Parties undertake to adopt immediate, effective and appropriate measures:
 - (a) to raise awareness throughout, including at the family level regarding PWD, and to foster respect for the rights and dignity of persons with disabilities;
 - (b) to combat stereotypes, prejudices and harmful practices relating to PWD, including those based on sex and age, in all areas of life; and
 - (c) to promote awareness of the capabilities and contributions of PWD (National Human Rights Commission of Indonesia, 2007, p. 12).

In the context of school programmes, there are at least three beneficial outcomes of disability awareness including: "1) increased acceptance by students without disabilities of their classmates with disabilities, 2) increased socialisation among all students, and 3) improvement of the perceived abilities of individuals with disabilities" (Lieberman and Houston-Wilson cited in Foley, Tindal, Lieberman & Kim, 2007, p. 34)

Research have shown that disability awareness can help dispel negative societal attitudes and beliefs that often create an additional barrier for PWD (Columna, Lieberman, Arndt, & Yang, 2009). It also can assist in tackling prejudice and building an inclusive society (Beckett, 2009; Safran, 2000).

To achieve the aims of disability awareness, the CRPD, in Article 8 (2) stipulates several measures:

- (a) Initiating and maintaining effective public awareness campaigns designed:
 - (i) To nurture receptiveness to the rights of persons with disabilities;
 - (ii) To promote positive perceptions and greater social awareness towards PWD;
 - (iii) To promote recognition of the skills, merits and abilities of PWD, and of their contributions to the workplace and the labour market;
- (b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of PWD;

- (c) Encouraging all organs of the media to portray PWD in a manner consistent with the purpose of the present Convention;
- (d) Promoting awareness-training programmes regarding PWD and the rights of PWD. (The National Human Rights Commission of Indonesia, 2007, p. 12).

The expression of disability awareness

Based on a review of the relevant literature, various expressions of disability awareness raising have been found to be in line with the CRPD's articles. It has provided me with an insight into disability awareness training and the audio-visual materials used to complement them. The following description of the present literature concerning disability awareness training as the most common expression.

Training is one of most common methods of disability awareness-raising (Hunt & Hunt, 2004; Ison, et.al, 2010; Krahe & Altwasser, 2006; Rillotta & Nettelbeck, 2007; Tavares, 2011). Rillotta & Nettelbeck (2007) conducted a quantitative study on a secondary student who had participated in a 10-session disability awareness training programme in Adelaide, Australia. This programme consisted of eight to 10 45-minute sessions of training completed with a video showing people's perception of disability and Down syndrome. This video was commercially produced. Tavares (2011) addressed her evaluation research on the 'Kids Are Kids' disability awareness programme in Canada, which involve 51 students, in grades 6 and 7, in four schools. This programme consists of sharing knowledge about students with disabilities, presenting PowerPoint slides, watching a video, discussions, brainstorming and informal roleplaying. The video was entitled "Kids just want to Have Fun" and highlighted children with special needs interacting with other children and engaging in a variety of social and recreational activities. From all of these research reports, I discovered that disability awareness training enhances students' sensitivity toward their peers or classmates with disabilities and their skills to appreciate the rights and dignity of people with disabilities. Thus,

disability awareness training enhances peoples' sensitivity toward PWD and their skills to appreciate the rights and dignity of PWD.

Simulation is another common expression of disability awareness raising (Fiittipaldi-Wert & Brock 2007; Flower, Burns & Bottsford-Miller, 2007; French, 1992; Herbert, 2000; Salend, 2005; Schuldborg, 2005). Simulation is also used as one of the training methods to provide an understanding of the challenges faced by people with disabilities. Simulation, generally, is conducted by setting up role plays. For example, some people act as disabled people, while others act as non-disabled people.

Some other creative disability awareness expressions include: the Sport Education Model in school curricula (Foley *et al.*, 2007); and the inclusion of disability sport in general physical education curricula (Davis, Rocco-Dillon, Grenier, Martinez, & Aenchbacker, 2012).

Furthermore, the literature also indicates that the most common disability awareness-raising strategy is training equipped with videos, or watching audiovisual media in the form of **online videos** (Bromley, 2008; Columna *et al.*, 2009; Salend, 2005), or **websites** and **films/movies** (Connor & Bejoian, 2006; Mitchell, 2008; Safran, 2000). Such audiovisual media are potent learning tools and effective pedagogical approaches because, amongst other reasons, audio visual media, such as video or film, "definitely brought to life more than what is in a textbook" (Schwartz, *et al*, 2010, p. 847). Research also supports that, compared with written materials, audiovisual materials are clearly an appropriate format that is accessible to wide and diverse audiences in this technological media-influenced age where so many people rely on visual images and are more visually literate. Accordingly, these media are also deemed interesting and suitable for a media-influenced society and people who are more visual than literate, such as children (Cruze, 2007). These activities involve fun and through these interesting activities, young people - as the future generation - are able to learn positive values and attitudes about disability. This is important as various studies, as have been described in the

previous section – the semiotics of disability - have reported that false beliefs about disability and negative attitudes towards PWD are acquired in childhood. People are not born with prejudice against people with disabilities, but attain and internalise this from adults, the media and the general way in which society is organised (Beckett, 2009; Kirkwood & Hudnall, 2006). Thus, it is expected that these young people can become key agents for social change with regard to disability.

2.3.4. Disability awareness videos

Some studies have established that audio visual media addressing disability awareness positively promotes respect for the individual differences, rights and dignity of people with disabilities (for example, Salend, 2005; Connor & Bejoian, 2006), with counter stereotypical views reducing resistance (Shapiro, 2000, p. 349). This audiovisual media includes:

- a. Compact discs (CDs) (Shapiro, 2000, p. 349),
- b. Videos (Bromley, 2008; Cruze, 2007),
- c. Films (Connor and Bejoian, 2006)
- d. Movies (Safran, 2000; Mitchell, 2008); and
- e. Digital video discs (DVDs) (Disability Service Commission, 2006).

These research findings resonate with a widely known learning axiom: “we learn 11% through hearing and 83% through sight; we remember 50% of what we see and hear and 90% of what we say and do” (Sayers, 2006, p. 9).

However, during the literature and material review, I did not find any articles, studies or videos about disability awareness in Indonesian context. Nor did I find material that specifically addresses how to develop a disability awareness video. Typing ‘disability awareness video’ into the Google search engine led me to thousands of videos on YouTube, containing this phrase in the title or tags. I then tried to narrow down the search with the keywords ‘disability awareness in Indonesia’, but this failed to produce any results.

I decided to view the first 30 videos that appeared in my search while also taking notes. From this review of the videos (see appendix C), I found that there was no video that directly or specifically explained the reason why they were tagged as 'disability awareness videos. However, it can be inferred from my review of the YouTube videos that disability awareness videos include any video that contains or delivers educational messages in the form of information relating to disability and PWD. These videos include: (i) an explanation regarding impairments, such as visual impairments or hearing impairments; (ii) guidelines or etiquette to deal with individuals with these impairments; and (iii) the portrayal of what it is like to live with these impairments. In addition, these disability awareness videos also contain informative messages that are conveyed in the form of personal stories of PWD, documentaries of their activities, documentary of their events, including interviews with them or about them, and also documentaries of disability awareness events. These videos, in general, are constructed with a specific purpose — meaning they are created with professional equipment supported by specific sponsors, which appears at the commencement or end of the videos. There are also videos created by amateurs using regular recording equipment, with poor techniques and little or no editing, leading to low quality recording, such as blurred images and poor lighting. Furthermore, the sound quality is also affected by background noise; for example, a car driving by, children playing games, and roosters crowing.

To summarise this section, the four topics selected centre on the relationship between the media and disability, as this informs my research and the production of a video to increase awareness about disability issues in Indonesia. There were limitations to these studies on audio-visual materials, such as the fact that the videos mentioned by these Western researchers were delivered in English, or other languages with English subtitles. These disability awareness videos were not inclusive of Indonesian contexts. This means they might not adequately address the lives and experiences of Indonesian PWD. In addition, the majority of the Indonesian society does not speak English daily, nor is familiar with non-Indonesian contexts.

Therefore, there are challenges to transferring these study results to very different contexts such as disability awareness in Indonesia. It also generated challenges and the need for this study to be aware of the possibility of conducting research on the appropriate audiovisual materials for disability awareness-raising in Indonesia with PAR without deeming this study to be judged as being inconsistent or having a dual character – being a research report and a program report or a description of an intervention (in the form of making of an awareness training video)

2.4. Disability Issues in Indonesia

This section provides a context for the research by examining how disability is considered by government through law and its public policies, as well as community and cultural consideration about PWD in Indonesia. This section begins with issues related to policy, statistics, definitions, cultural background, and ended with issues related to disability awareness in Indonesia.

2.4.1. Issues related to policy

Indonesia has a number of regulations relevant to and concerning PWD. The three main regulations are outlined in this section:

- a. The supreme law, as stated in the 1945 Constitution, Article 28 D (1), stipulates that “everybody is entitled to an acknowledgement, assurance, protection and guarantee of law that is just, and equitable before the law. This Article contains all of the principles of human rights, including the rights of PWD that are legally binding for all parties in Indonesia.
- b. Law Number 4 (1997), concerning disabled people (APCD, 2009, Irwanto et.al, 2010) provides a formal definition and classification of disability, and prescribes many of the rights of people with disabilities, including the right to obtain education, employment and a proper standard of living; equal treatment to participate in national development, accessibility, and rehabilitation; and especially in relation to children with disabilities. This law

was intended to be one of the foundations to advance the welfare of PWD in Indonesia.

c. Law number 39 (1999) concerning human rights, rules that is relevant to PWD states:

1. 'Every individual who is considered to be in a disadvantaged group is entitled to better treatment and protection in relation to their disadvantaged situation' (article 5: 3); and,
2. 'Every individual with disability — whether they be old, pregnant or a child — is entitled to accessibility and special treatment' (article 41: 2) (Irwanto, et.al. 2010, p. 21).

These two laws are significant and recognisable achievements of the Indonesian government from the Asian and Pacific Decade of Disabled Persons, 1993-2002 (Price & Takamine, 2003 as cited in Irwanto, et.al. 2010, p. 1). The Asian and Pacific decade was one of the significant international initiatives that generated avenues for emphasis on the world's concern and commitment to disability issues in the Asia-Pacific region. This decade was an extension of the internationally acknowledged UN Decade of Disabled Persons 1983-1992, during which December 3 was declared the International Day of Disabled Persons in 1992 (Wiman, 2003, p. 11).

However, despite these laws indicating the commitment of the Indonesian Government, they are not well enforced and their implementation has been weak due to the following reasons:

- The laws set out the importance of rights and equal opportunity for people with disabilities in various aspects of their life without explicitly specifying the agencies or ministries that should implement them;
- The laws are not reinforced by legally binding decisions;
- The laws are not supported by regulations specifying implementation measures;
- The laws do not specify funding for their implementation; and,

- The laws do not specify who would, and how to monitor and evaluate their implementation (Irwanto *et al.*, 2010, p. 17; Yulianto, 2011, pp. 48-49).

The Indonesian legal system is hierarchical, with the 1945 Constitution (*Undang-Undang Dasar 1945*) being on the highest tier. On the second tier are Laws (*Undang-Undang*), and as such every law needs to be based on the Constitution. On the third tier are Government Regulations (*Peraturan Pemerintah*), which are based on the Constitution and Laws. Government Regulations were developed as a guideline for the implementation of any law. The Constitution, Laws and Government Regulations are legally binding for all parties. Many Laws require lower legal instruments to allow for implementation, meaning that Laws cannot be implemented if lower-level legal instruments are not available. These include Government Regulations, Presidential Regulations (*Peraturan Presiden*), Ministerial Regulations or Ministerial Decrees (*Peraturan Menteri*), or Circular Letters from Ministries, and local ordinances. These lower-level instruments are not legally binding, but usually serve as guidelines or suggestions for an issue. 'The provisions in those instruments become the benchmark for implementation at the local and community levels' (Irwanto *et al.*, 2010, pp. 21-22). However, there are discrepancies between the existing normative framework/legal instruments and the resources provided to enforce the rights of Indonesian people with disabilities. Another problem is that there is no harmonisation of policies among Laws concerning PWD. For example, Law Number 4/1997 is not supported by an adaptation of other laws. This reflects the fact that Indonesia at this time lacks the genuine political will to achieve the goals of disability legislation and policies (Yulianto, 2011, p. 48). Thus, it could be concluded that, despite all of these achievements, the rights and needs of Indonesian PWD are not guaranteed enough by existing Indonesian legislations.

Meanwhile, in order to effectively promote and enact the idea of an inclusive, barrier-free and rights-based society for PWD in the Asian and Pacific region, UN ESCAP declared the extension of the Asian and Pacific Decade of Disabled Persons (1993-2002) for another decade: 2003-2012 (UN ESCAP,

2002, p. 3). The Indonesian Government responded to this decade by ratifying the UN CRPD and enacted its ratification into Law Number 19 of 2011 regarding the ratification of the Convention on the Right of Person with Disabilities. The CRPD provides a legally substantial resource through which 22 rights of PWD can be claimed.

Therefore, Law Number 19 of 2011 already has nuances of human rights where discrimination on the basis of disability is illegal and non-constitutional. This Law offers the hope of abolishing discrimination and stigma attached to Indonesians with disabilities. It also provides a new opportunity to revise Law Number 4 of 1997, and create a standard across all relevant laws and incorporate the social and rights-based model into existing programmes and policies. Although there is evidence of the Government having taken steps to diminish ableism and fulfil its obligations for its people, there needs to be a significant forum in which all Indonesian PWD can participate. They should be able to voice their interests and needs without being dependent on those who do not experience disabilities. Indonesian PWD know their own lives very well and their voices need to be heard in policy or regulation processes.

With reference to policy or regulation processes, Rogers and Dearing (in Parsons, 1995, p. 115) state that in the policy-making process: “personal experiences and interpersonal communication” is an important input for the policy agenda. In the disability context, these experiences and communications refer to the voices of PWD, which need to be taken into account in the policy process as mentioned above.

Moreover, Roger and Dearing also explain about “how the policy agenda is determined by two other agendas, namely the media and public agendas”. Nevertheless, these agendas can also be influenced by the personal experiences and interpersonal communication of PWD.

Thus, it is inevitable that the aspirations of the disabled should be voiced more in order to have a significant impact on the media and public agenda, which in turn will meaningfully affect policy.

The current existing Indonesian policy concerning PWD has not fully met the needs and interests of PWD because, amongst others things, the policy process does not incorporate their personal lived experiences as valid and important sources of knowledge. For example, it has been revealed that Law Number 4 of 1997 came into force around seven years after its drafting and legalisation process, which involved several Indonesian disabled people organisations (DPOs). Unfortunately, the legalised Law is different from what was drafted and agreed by the DPOs (Yulianto, 2011, p. 46). This fact disappointed the PWD actively involved in the process. This fact, the CRG participants argue, is one example that reflects the fact that disability is not a government priority, and Indonesian PWD are underestimated. Furthermore, this case reveals that the Government only paid 'lip-service' to these people's involvement and their lived experience has not yet been fully appreciated as a valid and important source of knowledge for policy.

2.4.2 Issues related to the statistics of PWD in Indonesia

Statistics on Indonesian people with disabilities are one of the key disability issues in Indonesia that make it difficult to describe the population of people with disability in Indonesia. There is little agreement on the national standards used to identify people with disability in the census and surveys in Indonesia, although Law Number 4/1997 provides a definition and classification of disability (Suharto, 2010, p. 2). This complicates ways of describing the population of people with disabilities in Indonesia, since there are a number of versions of statistical data. However, this not only occurs in Indonesia, but is also the case in other developing countries, such as South Africa (Heap, Lorenzo, & Thomas, 2009). This supports Altman's argument that one of the biggest challenges countries face in the collection of disability data is the translation of definitions and the operationalisation of these definitions into questions and methodology (Altman, 2001, pp. 93-94). Me & Mbogoni (2006) have also explained that problems with the wording of disability questions have not always encouraged a positive or even a neutral reaction by respondents

and interviewers. As a result, the figures on disability vary across different regions or time periods.

According to the national census conducted by the Indonesia Bureau of Statistics (IBS) in 2006, the estimated number of PWD in Indonesia was 3,063,000, which equates to 1.38% of the total population of Indonesia (United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP), 2010, p. 34), and they live in every part of Indonesia.

While result of Indonesia population census 2010 by the IBS (*Badan Pusat Statistik/BPS*) revealed that total population of Indonesia was 237,641,326 inhabitants, where 2,71 % of the total was the number of Indonesian PWD (<https://bps.go.id>). It equates to approximately 6,440,080 PWD above 10 years old age.

The number of Indonesian people with disability can be assumed to have increased following several recent natural disasters in many areas over the years. Indonesia is a country with a range of disability risks due to natural disasters (Masduki, 2011, p. 7), malnutrition, and traffic accidents (Irwanto et.al, 2010, p. 1). Indonesia is prone to natural disasters such as floods, earthquakes, tsunamis, landslides, volcano eruptions and forest fires, and is also vulnerable to high rates of malnutrition. This facts is in line with Ingstad's statement: 'wars, civil conflicts, natural disasters and environmental poisons along with the effects of normal ageing, accidents and poverty have combined to make the worldwide population of disabilities an ever-growing public health and civil rights issues' (Ingstad, 2001, p. 788).

2.4.3 Issues related to the definition of disability

Another important issue related to disability in Indonesia is how it is defined. In Indonesian regulations, there is no specific formal definition for disability, and only states formal definition of a person with disability. Meanwhile, the CRPD and many countries, such as Australia, Japan, the Republic of Korea,

Bangladesh, Nepal, Singapore, Thailand, and the Philippines have stated their own definitions of disability and people with disabilities (UNESCAP, 2010, p. 19).

In Indonesia a formal definition of people with disability is set out in the national legislation as follows (free translation):

A person with disability is someone who has physical and/or mental abnormality, which could disturb or be seen as an obstacle and constraint in performing normal activities, and consists of (a) person with physical disability, (b) person with mental disability, (c) person with physical and mental disability (Law of the Republic of Indonesia-Law Number 4/1997, concerning disabled people, p.1).

Law Number 4/1997 is the main source of official references regarding a formal definition and classification of disability in Indonesia. This Law's classification of disability is limited/not adequate because it covers various physical, mental conditions and multiple disabilities (physical and mental) which may range from mild to severe. Furthermore, disability is defined only in terms of medical abnormality and as an individual limitation in performing a 'standard' defined as 'normal' activities. It is a common case in the Asia Pacific region that governments' definitions of disability are linked with impairment, abnormality, and limitation. Besides Indonesia, UN ESCAP (2010) reports that Azerbaijan, Bangladesh, China and New Zealand also associate disability with abnormality. Cambodia, Fiji, Japan, Kiribati, Lao People's Democratic Republic, Mongolia, New Zealand, Pakistan and Vietnam define disability as a limitation of activities caused by individual impairment (p. 12).

The definition of disability in Law Number 4/1997 reflects the dominant view of addressing disability in governments, and more generally Indonesian society, as well as in the Asia-Pacific region. It is a view based, often unthinkingly, on the Medical Model and a Charity Model, which perceive people with disabilities as incapable and unequal. Ultimately, such definitions are both reflective of, and reflected in, Indonesian people's attitudes towards people with disabilities,

and how the Government responds to disability issues. This is based on the Medical Model, as it views disability as an abnormality that limits individuals, and locates the 'problem' of disability within the individual.

The main causes of disability discrimination in Indonesia are socially-located barriers faced by PWD (Masduki, 2011, p. 29; Yulianto, 2011, p. 36). Indonesia has insufficient societal infrastructure to deal with these barriers from/within the medical rehabilitation perspective of the Government and the charity approach of the non-government sector. This is in line with what has been identified by Isaac, Raja, and Ravanan (2010):

“... issues of discrimination and inequality cannot be addressed properly by national disabilities policies that emphasise too much on rehabilitation, individual support and disability prevention, and that most government services for disabled people are still small-scale rehabilitation projects separate from the rest of the community” (p. 629).

These factors combine to reveal that the Indonesian Government still inadequately provides for the inclusion and integration of Indonesian people with disabilities into able-bodied society (Suharto, 2011, p. 2). It has been argued that most of the barriers could be avoided not through rehabilitation but by means of “careful planning, legislation, public education and [disability] awareness campaigns together with the development of a Disabled Peoples’ Organisation (DPO)” (Kuno, 2007, p. 11), and “participation of people with disabilities” (Isaac *et al.*, 2010, p. 629).

Improvement and inclusion for PWD, as argued by Tsaputra (2011), is a challenge for Indonesian activists with disability, and needs national attention, supported by a powerful movement and media campaigns. Otherwise, Indonesian PWD will fall down the Government’s list of priorities, in favour of other issues deemed more important by the Government (Tsaputra, para 17-18). These ideas reflect a fundamental need for disability awareness to change the mindset from a Charity and Medical Model to a Social Model, which values PWD as citizens who have equal rights and can contribute to society.

This argument is in line with research on disability in low-income countries (Isaac *et al.*, 2010) which reveals persons with disabilities, along with their families, are amongst the most marginalised in every society. Regardless of a country's economic situation, history has shown that people with disabilities tend to be forgotten in the context of human rights, despite the inclusion of people with disabilities being one of the most essential fulfilments of universal human rights. This is an issue linked to social justice and it is an integral investment for the future of the society. Disability impacts the community as a whole, not just the individual with the disability. "The cost of creating barriers for people with disabilities from taking an active part in the society is high and becomes the responsibility of the said society" (Isaac *et al.*, 2010, p. 629).

Since the early years after the Declaration of Independence in 1945, several terms have been used in Indonesia to address persons with disability. In daily interaction in Indonesia, previously, individuals with impairments were called *orang cacat* (literally translated as 'person flawed'). This term then changed to *penderita cacat* (literally translated as 'sufferer of defect'). The term changed again to *penyandang cacat* (literally translated as a 'person with defects'). Around the 1990s, activists with disabilities and their supporters developed the terminology '*difabel*' as an abbreviation of 'differently abled' (Suharto, 2011, p. 52). The latest terminology is *penyandang disabilitas* (literally translated as 'people with disabilities'). This term introduced since around 2010 in line with international developments and the ratification of the CRPD into Law Number 19 of 2011.

2.4.4 Cultural background

Discriminative behaviour of the majority of the Indonesian public toward PWD is closely related to public understanding of the latter. The way Indonesian people define, or understand, and treat PWD nowadays is not unaffected by the attitudes and beliefs imported from Western Europe and other areas of the world due to colonialism.

As a brief overview, Indonesia was colonised by the Portuguese for a short time before the Dutch first arrived around 1596 for trade. From this point on, the Dutch spent roughly the next 300 years — from 1800 to 1942 — colonializing the entire nation. During World War II, the Japanese occupied Indonesia for several years until Indonesia gained independence on August 17, 1945. The influence of the Portuguese, Dutch, and Japanese was mostly in terms of language, architecture, the education system, and law. Therefore, this history demonstrates that the influence of colonisation became part of Indonesian culture (Thohari, 2013, p. 56-62).

Western societies highly value physical strength and adroitness (Rothman, 2003, p.17), having a 'beautiful figure' and being 'physically attractive' (Zastrow, 2004, p.546). Therefore, the colonisers perceived PWD as not fitting in with many of these values, so they were often kept apart from others in a form of social isolation. Accordingly, PWD experienced social exclusion (Rothman, 2003, p. xiv; Shapiro, 2000, p. 157), and were pitied as being less fortunate, and given sympathy. This led society to believe that PWD 'ought' to feel inferior (Zastrow, 2004, p. 546). This was an underlying reason for PWD to experience much discrimination and abuse. It also led to a lack of respect for people who have different appearances, and why they were considered not to be of equal value to the rest of society. Thus, it can be inferred that the colonisers judged and treated PWD based on the Charity and Medical Model. Furthermore, due to their impairments, Indonesian PWD were assumed to be unproductive, so they needed to be 'normalised' through nursing homes or rehabilitation institutions.

The history of disability in Indonesia can be seen from the period of Dutch colonialism, when nursing homes were built by the army of the Netherlands around the year 1621. After the liberation war, and Indonesian Independence in 1945, these nursing homes and the medical houses built by the Dutch colonial Government were taken over by the Indonesian Government to be used to rehabilitate the Indonesian military forces who had become disabled during the war (Yulianto, 2011, p. 13; Thohari, 2013, p. 59).

However, before the colonial era, it was revealed that the Indonesian society, and mainly those living in Java, lived in harmony and respected one another (Nugroho, 2013). People who had differences due to impairment were perceived as human and treated with the same level of respect as the rest of the able-bodied society. Thus, the image of PWD during the pre-colonial era was not negative. Indonesian culture, and the Javanese culture in particular, appreciated the importance of living in harmony. This is further evidenced by stories of Javanese traditional puppets (*wayang*), where the characters are very diverse and include those with disabilities — such as *Destarata*, who is visually impaired, and *Semar* and *Petruk*, who are physically disabled, yet treated respectfully and not stigmatised, and even considered to have some sort of divine power (Carey, 2013). Javanese society perceived wayang characters who had impairments as figures to be admired and respected (Thohari, 2013).

2.4.5 Disability Awareness in Indonesia

Disability awareness in Indonesia is mostly related to ceremonial with the ritual annual conduct of an international day of PWD on December 3rd, having done little to change the lived experience of PWD (Fuad, 2009). Some Indonesian PWD, especially those who have higher education and have experienced tertiary education in an international setting, feel dissatisfied with these social conditions. They have identified a gap between how disability awareness currently exists and how it is expected by most PWD in Indonesia. They insisted that it needed and could be changed for improvement in their lives. They wanted change and improvements in disability awareness and their lives.

A small group of alumni of the University of Indonesia, which is comprised of those who have disabilities and have mostly graduated with a postgraduate degree from overseas universities with scholarship support from international funding bodies, established the Disability Studies Centre of the University of Indonesia (DSC-UI) in mid-2006. They emphasised the critical importance of disability studies as a way to improve both government and community

responses to the needs of Indonesian PWD. Amidst slow and limited support and sponsors, in 2009 the DSC-UI commenced a pioneering effort to build an inclusive society by providing disability awareness through extension training to the community, starting with the University of Indonesia's *civitas academica* (an academic community with strong solidarity between students, academic staff and non-academic staff). The DSC-UI provided training to students, academics and non-academic staff of the University of Indonesia.

As a brief overview, the DSC-UI's disability awareness training comprises six hours of sessions covering information on eight types of disabilities and instructions on how to communicate and help individuals with each disability. This information was presented using 51 PowerPoint slides, which were followed by disability games, simulations and discussions. These sessions are delivered by two trainers from the alumni group – one with a disability and one without. The establishment of a training team that consists of persons with disability and persons without disability was one of the breakthroughs from this awareness-raising initiative, and had never been done before in Indonesia (Widinarsih, 2012). Their way of delivering such training resonates with Shapiro (2000), who discusses disability awareness training in the US, and with Ison *et al.* (2010) who has reported on a similar training programme in Australia entitled 'Just Like You'. It also resonates with Tavares's (2011) study, who evaluated the 'Kids Are Kids' disability awareness programme in Canada. The underlying differences between the DCS-UI disability training and these three reports is that the DSC-UI programme has not yet utilised audio-visual materials such as movies or videos (Shapiro, 2000, p. 349). This issue was revealed in an evaluation by the participants of this programme, who agreed that audio-visual media and materials would complement the training well. This suggests that there is a need for the DSC-UI's disability awareness training to be complemented by a disability awareness video. Ironically, despite living in a media-influenced society, it was difficult to find audio-visual media specifically designed as disability awareness videos in or about Indonesia.

Meanwhile, other researchers reported that there was plenty of audiovisual media that could be used to support disability awareness-raising activities. These include, for example, popular films and movies (Connor and Bejoian, 2006; Safran, 2000) and videos from free websites on the Internet (Bromley, 2008), which are also called online videos (Columna, Arndt, Lieberman & Yang, 2009). There was general agreement in the literature (see, for example, Bromley, 2008; Connor & Bejoian, 2006; Salend, 2005; Mitchell, 2008) that a video is the most accessible and engaging format to raise positive disability awareness for as wide an audience as possible. Unfortunately, the videos mentioned by these Western researchers are delivered in English, or other languages with English subtitles, and so are not inclusive of the Indonesian context. This means they may not adequately address the lives and experiences of Indonesian people with disabilities. Further, the majority of Indonesian society does not speak English daily, nor is familiar with non-Indonesian contexts. Therefore, to avoid misinformation and misunderstanding amongst this audience, there needs to be detailed modifications and preparation before these videos could be applied to an Indonesian context.

2.5 Summary of chapter

A review of the recent literature reveals a lack of non-Western research about disability, and provides the rationale to develop this study as an original contribution to the unexplored disability experiences in a non-Western context, with particular reference to Indonesia. This review is divided into four broad sections. Firstly, it discusses understandings of disability; secondly, rights and disability are focused on; thirdly, issues related to media and disability are analysed; and finally, disability issues in Indonesia are focused on.

This chapter has highlighted some of the important aspects to consider when conducting a PhD on disability awareness with PWD in Indonesia. This study draws on the social model of disability and takes into account Indonesian policy and cultural contexts.

CHAPTER THREE

RESEARCH METHODOLOGY

This study involves collaboration with a purposive sample of Indonesian PWD to achieve three objectives: First, to describe and analyse the realities of PWD life in Indonesia; second, to explore and analyse key issues related to the current disability awareness in Indonesia; and finally, to develop disability awareness-raising strategy as proposed by the research participants.

This chapter is organized into two parts: methodology and research methods. Section one covers the research methodology, and the remaining sections present the research methods. Section one begins with a justification for the use of Participatory Action Research (PAR), followed by a description of the origins of PAR, its meaning, purposes and characteristics, challenges and critiques to PAR. This section ended with reviews of previous scholarly studies relating to the application of PAR. The second section covers the details of this particular study. It includes discussions on the research sampling techniques used, the data collection methods, the method of data analysis/interpretation of findings, a discussion of the rigour of the methods, and finally a description of the ethical issues related to this study.

3.1. METHODOLOGY

3.1.1. PAR as the principal research approach

This study employed PAR as the principal research approach. It has been described by several authors as more than simply a research method, and stating it is:

“An ontology that suggest that human beings are dynamic agents capable of reflexivity and self-change, and an epistemology that accommodates the reflexive capability of human beings within the research proses” (Kindon *et al.*, 2010, p. 13)

As such, PAR can be regarded as “more than a methodology - it is a ‘political statement’ and ‘theory of knowledge’” (Klocker, 2012, p.150) because it has the ability to privilege “insiders” with intimate knowledge rather than simply involving “outsiders” or experts, through:

- “Recognising the existence of plurality of knowledge in a variety institutions and locations...PAR therefore represent a counter hegemonic approach to knowledge production” (Kindon *et al.*, 2010, p.9);
- “Constituting a direct affront to the traditional separation between academia and activism (Tandon, 1998 cited by Klocker, 2012, p.150)

Therefore, PAR is the most compatible approach with the Social Model of Disability which advocates for the equal rights and inclusion of PWD, because it recognises that the lived experiences of PWD is a source of knowledge and expertise (Hergenrather & Rhodes, 2002, p. 60). PAR goes against ‘the facts’ of disability research that have been dominated by experts and professionals. It places particular importance on acknowledging that marginalised groups have specific knowledge of their own lives which needs to be valued. PAR also promotes the active involvement of those who are usually the ‘subject’ of the research in traditional methods. In PAR they are active collaborators. It tries to reduce the distance between the researcher and the ‘research subjects’ (Katsui & Koistinen, 2008, p. 1).

PAR is congruent with two key features of the Social model of disability; firstly, it challenges the academic research conducted without the collaboration of PWD themselves (Cree and Davis, 2007); and secondly, it facilitates the research and removal of the barriers and limitations placed on PWD by an inaccessible world (Oliver, 1992; Barnes, 1992, 2003). Thus, PAR is congruent with and promotes the inclusive spirit of the Social Model, which assigns important roles to PWD in disability research and respects them as equal, valued, and capable people. As such, no voice is silenced because PAR emphasises that people with disabilities are experts and their lived experiences are vital source of knowledge.

PAR also fits with the objectives of this study, which are intended as a response to the unsatisfactory conditions concerning the social inclusion of PWD and disability awareness issues in Indonesian society. PAR increases the prospect that research will be “appropriate, meaningful and relevant” to communities (Kesby et al., 2005, cited by Klocker, 2012, p. 150). Moreover, implementing PAR on disability awareness is a significant way to improve civil rights for both people with and without disabilities because of the interrelation between the two groups:

The boundaries of the disability community are permeable. Anyone can become a member at any time, whether through injury or illness. Integrating disability into the dialogue on diversity and oppression therefore has a wide application for those who are currently disabled as well as for those who are not (Gilson & DePoy, 2002, p. 163).

To give further insight into PAR, the following sections will describe the origin of PAR, its meaning, purpose, and characteristics, the degree of participation in PAR, along with the challenges and critiques of PAR, ending with a description of previous scholarly studies relating to its application of PAR.

3.1.2. The Origins of PAR

There are a number of different accounts and interpretations which describe the origins and development of PAR (Kindon *et al.*, 2010, p.9) for the following reasons:

The origins and development of PAR are both complex and difficult to map with any precision. It is not only because the term is used loosely and often interchangeably with concepts such as action research, but also because PAR is itself a blend of a broad range of research approaches and epistemologies that includes participatory research, action research, feminist praxis, critical ethnography, Aboriginal research methodologies, transformative education, critical and ecopedagogies, and popular education (Jordan, 2008, p. 3).

Nonetheless, there is consensus on some of the main attributes of PAR's historical development. The main points are summarised below.

Historically, PAR emerged around the 1960s –1970s in developing countries, such as Africa, India, and South America (Jordan, 2008, p.3; Kindon *et al.*, 2010, p. 10). It was intended to be a response to the oppressive or exploitative conditions resulting from colonisation. Much of this was linked to the independence and civil rights movements of the post-World War II period (Jordan, 2008, p. 3; Kindon *et al.*, 2010, p.10). These liberationist forces were often characterised as being people's movements, and this process of participation also informed new approaches to research.

During this period, scholars such as Paulo Freire in Brazil and Orlando Fals-Borda in Columbia, Rajesh Tandon in India, and Marja-Liisa Swantz in Tanzania started to engage in efforts where "social science research could be used to relocate the everyday experiences and struggles of the poor, oppressed, and marginalized from the periphery to the centre of social inquiry" (Jordan, 2008, p. 3; Kindon *et al.*, 2010, p. 10).

PAR has also emerged as the fourth generation of action research. It was initiated in developing countries to challenge the unsatisfactory conditions where research was mostly privileged *value-free* knowledge of Western positivist paradigms and dominated by academic researchers working in universities within the advanced capitalist world of the global north countries. Accordingly, Western positivist and academic researchers' ideological orientation has focused on improving scientific methodology and professional practices (Kemmis & McTaggart, 2008, p. 272; Jordan, 2008, p. 4).

Thus, it can be concluded that the idea of PAR emerged around the 1960s–1970s in the context of social movements in developing countries as a response to the unsatisfactory conditions resulting from colonisation and the

domination of positivistic research paradigms adopted by university-based researchers in the Western world.

3.1.3. The meaning, purpose and characteristics of PAR

3.1.3.1 The meaning and Purpose of PAR

PAR is basically a research approach that “involves researchers and research participants working actively in partnership in order to achieve a shared understanding of issues and problems and bringing about change” (Wadsworth, 1993, p. 1). An important notion within this research is that of dialogue, genuine collaboration (Reason, 1998, p. 270), and close and active interaction between the researchers and participants. This exchange is ultimately aimed at action towards the resolution of social contradictions (Cocks & Cockram, 1995, p. 35). Accordingly, PAR is mostly driven by the ‘need to know in order to produce desired change upon current problematic action’ faced by researchers and participants (Wadsworth, 1993, p. 1)

PAR’s purpose as a methodology is more inclusive and participatory, and it does not offer one particular strategy for research endeavours. It is “rather the creation of a context in which knowledge development and change might occur-much like building a factory in which tools may be made rather than necessarily using tools already at hand” (Kidd & Krall, 2005, p.187). “PAR is an ‘orientation to inquiry’ that values the processes of research and the research experience as much as the products (Kindon *et al.*, 2010, p.13)

The products of PAR vary; they may include a strategic plan for a Disabled Peoples Organization (DPO) (Radermacher, 2006), group gathering and meeting with the decision maker on the problem to be solved (Valade, 2004), the creation of the disability movement (Katsui & Koistinen, 2008), awareness raising project such as a research project website (Ollerton & Horsfall, 2013), video (Parr, 2007; Hume-Cook, 2010), an action plan in which one of its components is video (Kreitzer *et al*, 2009), and drama (McFarlane & Hansen, 2010)

PAR incorporates many of the values and principles of Social Work, such as social justice and people becoming actors in the process of change (Cassano & Dunlop, 2005, p. 2; Dudley, 2005, p. 30). It enables the participants to work as a collective, sharing objective and subjective aspects of reality facilitated by eliciting and analysing the common knowledge these people possess, which is complemented by the researcher's view of reality (Selener, 1997, p.20). Thus, PAR respects the participants as capable agents, putting them in an equal position as important stakeholders during the research process, and emphasizing collaboration and dialogue among the stakeholders of the research.

3.1.3.2. The cycle and Characteristics of PAR

As a research approach, PAR is characterized primarily by its cyclical research process, defined by cycles of action:

Instead of a linear model, participatory action research thus proceeds through cycles... reflection, raising of questions, planning of 'fieldwork' to review current (and past) action – its conduct, analysis of experiences encountered, the drawing of conclusion, and the planning of new and transformed actions – that characterises all research endeavour” (Wadsworth, 1993, p.3; Wadsworth, 1998, p.5)

This explanation of PAR's dominant characteristic is directly equipped with a basic illustration of the cyclical research process by Wadsworth that reproduced here in figure 3.1. (Wadsworth, 1993, p.3; Wadsworth, 1998, p.5)

“fieldwork” =
intensive seeking of
answer-checking
and challenging of
hunches

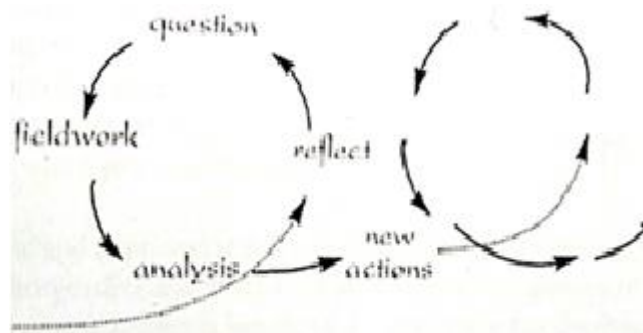


Figure 3.1. Wadsworth's cyclical research process of PAR

Hence, there is general agreement that PAR's cyclical process essentially consist of four stages or steps¹:

The **Observation/observing** stage involves describing what actually happened during the processes, and collecting data to answer questions (research questions and/or any question that surfaced during the research processes).

The **Reflection/reflecting** stage involves analysing the observations throughout the PAR process, and reviewing current and past actions It concludes with a consideration of what else needs to be planned.

The **Plan/planning** stage involves planning changes based on recommended actions from the reflection stage.

The **Action/acting** stage involves implementing the plans to produce the desired changes.

(Alston & Bowles, 2003, p.163; Kemmis & McTaggart, 2008, p.278; Quixley, 2008, p10.; Wadsworth, 1984, p. 44).

The above-mentioned PAR's four steps of the cyclical research process are followed with illustration presented in Figure 3.2. This figure was reproduced from Quixley who formulated it as a working PAR model to simplify the cyclical PAR research process, which actually is quite complicated to demonstrate (Quixley, 2008, p.9)

¹Kemmis and McTaggart used both terms: steps (2008, p.276) and stages (2008, p.277); Quixley used 'steps' (2008, p.10), while Wadsworth did not specifically use either of these terms, but explained the process in details and confirmed it as characteristic of PAR. This study use both terms interchangeably.

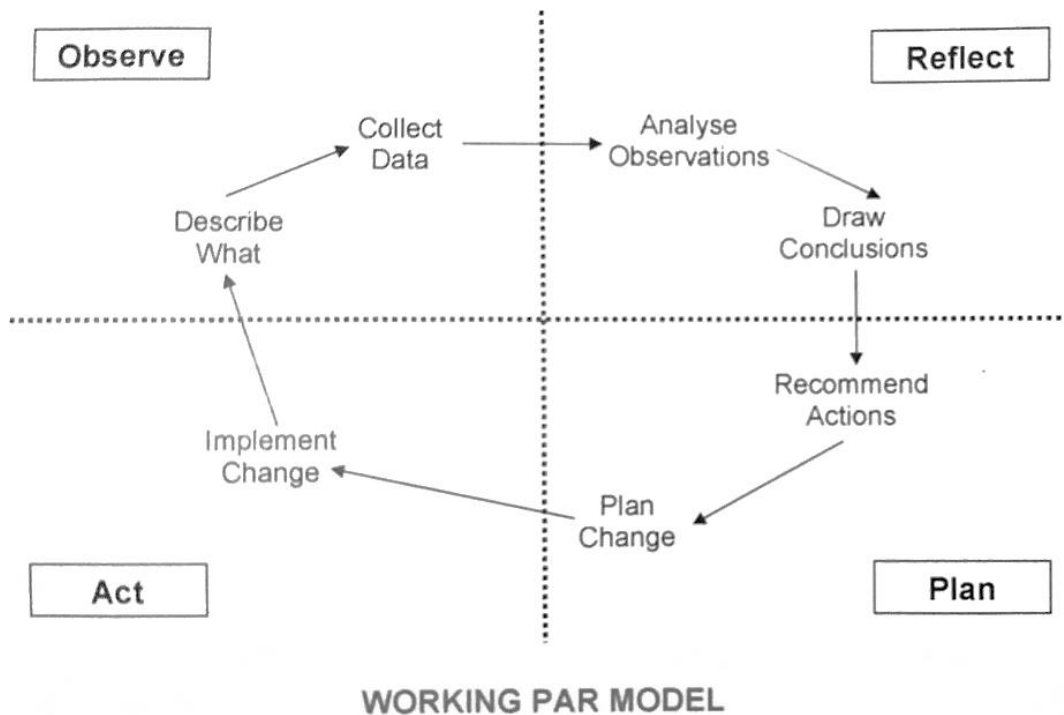


Figure 3.2. Working PAR Model (Quixley, 2008, p.10)

This study support this working PAR model of Quixley. It gives a clear illustration of the dominant characteristic of four PAR steps. Quixley claims that the framework above is “a simplified version of the model, to make it easier to talk about specific steps and processes” (Quixley, 2008, p.10).

Moreover, PAR’s cycle- as suggested in the relevant literature - is not a fixed pattern, which moves seamlessly from planning, acting, and observing and ending with reflecting in the research process (Willis, 2007, p.269)

Please note that a cycle does not necessarily begin with Planning. It could be begin with any of the other processes-Acting, Observing or Reflecting... Steps are constantly repeated throughout the process... A Cycle can take anything from few hours, to a few years, to complete... Circle can overlap one another (Quixley, 2008, p.10)...In real life, it is difficult to separate the Action stage from the Observation stage” (Quixley, 2008, p.11 Kemmis & McTaggart, 2008, p.278)

In reality, the process is likely to be more fluid, open, and responsive. The criterion of success is not whether participants have followed the

steps faithfully but rather whether they have a strong and authentic sense of development and evolution in their practices, their understandings of their practices, and the situations in which they practice (Kemmis & McTaggart, 2008, p.277)

However, looking at Figure 3.1, Wadsworth has a slightly different emphasis than others which is summarised in the following statement:

Instead of a linear model, participatory action research thus proceeds through cycles, **'starting' with reflection** on action, and proceeding round to a new action which is then further researched. The new actions differ from the old actions-they are literally in different places...There is *always* new action resulting-even if it is just the same as the old (which we might describe as reproducing the 'status quo')(Wadsworth, 1993, p.3; Wadsworth, 1998, p.5 – emphasis added)

Accordingly, PAR has been described as fluid, multifaceted, co-created and idiosyncratic (Ollerton & Horsfall, 2013, p.620). Its iterative cycles, are in fact complicated to demonstrate with ease due to “the high level of flexibility in PAR” (Quixley, 2008, p.9).

As an approach, besides the dominant feature of PAR's iterative cycles, it has eight essential characteristics. These include a focus on change, inclusive processes, addressing real-life issues, being community-centric, and treating diversity as enriching to research process. PAR acknowledges that the community and participants have the capacity to produce knowledge, so they should be an integral part of the research process (Kindon *et al.*, 2010, p. 14).

Another seven principal characteristics of PAR were identified by Kemmis and McTaggart (2008, p. 280), and are clearly very similar to those identified by Kindon, Pain and Kesby (2010). Firstly, PAR is a social process, which means that it is important for individuals to actively find solutions to their struggles within a social context. Secondly, PAR is participatory, encouraging all those involved in the problem to participate actively in the resolution process. Thirdly,

PAR is practical and collaborative, which means that it is based on real problems experienced and named by peoples affected by these problems who collaborate with the researchers to develop practical and useful knowledge. Fourthly, PAR is emancipatory, in that the process deems the lived experience and knowledge of people affected by the problems as instrumental to the process of deciding upon the problem, investigating what they need to learn in order to help solve the problem, and implementing some form of action based upon their learning and experiences.

Kemmis and McTaggart (2008) also suggested that PAR is critical since it emphasizes an attitude of critical inquiry. This involves trying to look at the problem from a variety of facets and to assess which steps will offer some form of resolution. Reflexivity is another important characteristic of PAR that refers to the attitude and practice of taking the time and energy to ask questions about what has been learned, what worked, and what did not. This then involves bringing these insights back into dialogue with the co-researchers to communally learn from each other, and as preparation for the next phase. Finally, PAR aims to mutually influence both practitioners' theories and practices, and the theories and practices of others whose perspectives may help to shape the conditions of life and work in particular local settings. All these key features highlight the importance of community participation; engaging people to examine their knowledge and investigating the reality of their lives in order to develop their own strategies to change and improve their lives.

3.1.4 The degree of participation in PAR

"PAR is just like its name: *participation*-“to have a part or share in something”- and *action*-“the bringing about of an alteration using research as a tool” (Kidd & Krall, 2005, p.187). Hence, participation is a vital characteristic, but it is also crucial “to avoid ‘being puritanical’ about the need to do participation thoroughly or not at all” (Kesby et.al in Klocker, 2012, p.158) due the view that “efforts at participation which do not achieve the ‘ideal’ have been described

variously as weak, false and unreliable, untrustworthy, unfruitful and disappointing (Klocker, 2012, p.157).

This assumption is commonly related to considering participation as hierarchical, in that it starts from a point where there is little or no participation, to the peak where participants have and are in total control.

Thus, it is vital to acknowledge that in reality when conducting PAR, realistic participation includes, or means:

- Thinking of participation as non-hierarchical, but in a continuum, since the level of participation by co-researcher and participants may vary significantly. Thus, there are modes and degrees, or diverse levels of participation within PAR (Katsui & Koistinen, 2008, p. 753; Kindon *et al.*, 2010, p.15);
- Various form and modes of participation may be valid at different times during a research process and may also be unique to each situation and context (Kidd & Krall, 2005, p.1889);
- “People are provided with the opportunity to participate in whatever way they desire and they have choices to participate”. This includes respecting if co-researchers or research participants want to work on their own terms. (Kindon *et al.*, 2010, p.16; Radermacher, 2006, p.57).

Furthermore, with regard to non-hierarchical participation, there are six-**degrees of participant involvement in PAR**, which emphasise that “each form of participation can be regarded in its own right, with its own unique set of characteristics, with the type of participation that a person is engaged with being dependent upon the context” (Radermacher, 2006, p.27). This is displayed in the Figure 3.3.

I found this illustration helpful when compared with the illustration of non-hierarchical participation by Kindon *et.al* (2010) which still gives the impression of hierarchy due to it being built from the ground up starting with ‘passive participation’ and leading to the pinnacle of ‘self-mobilisation’(p.16).

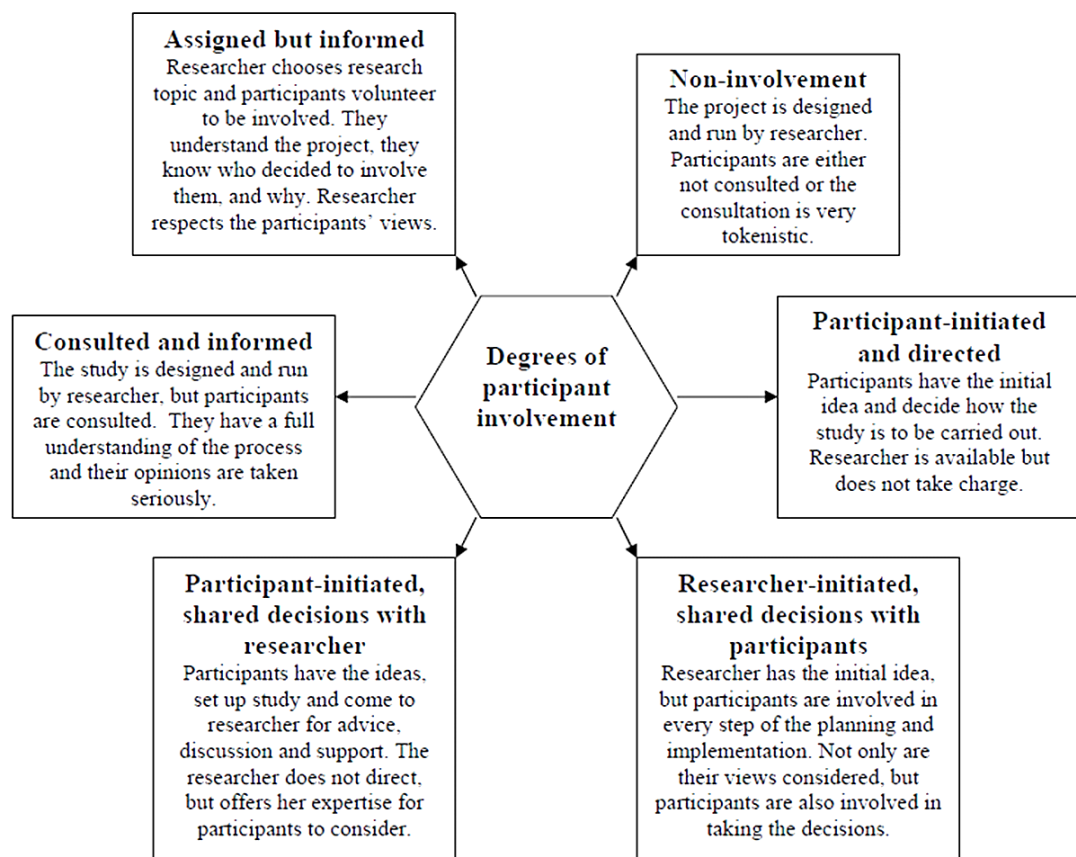


Figure 3.3. Six-degree model of participant involvement in PAR
(Adapted from Fajerman & Tredesen, 2000 by Radermacher, 2006, p.27)

However, the author (Radermacher, 2006) did not specifically explain in detail about the order or sequence of the degrees. As such, I presumed that degrees of participation in PAR vary from: non-involvement; assigned but informed; consulted and informed; participant-initiated and directed; participant-initiated, shared decisions with researcher; to researcher-initiated, shared decisions with the participants.

This illustration also clearly supports graduate students attempting to conduct PAR in accordance with the academic requirement, because it is in line with the following two arguments: “that it is perfectly **acceptable** for academic researchers to *initiate* participatory endeavours” (Maguire, 1987, p., Kidd & Kral, 2005, p.188). “By being aware of my subjectivities and biases, ultimately I found that this process did **not jeopardize** my intention to conduct PAR” (Klocker, 2012, p.153). Hence, it is **not unethical** conduct to initiate PAR as

long as the researcher's "attitudes is frame of mind includes respect, genuineness, and a good dose of openness to experience, joint commitment and responsibility" (Kidd & Kral, 2005, p.188).

3.1.5. Challenges and criticisms of PAR

PAR as a research approach has been successfully applied in a number of different settings and contexts worldwide, especially among people who experience problematic situations or live under oppressive or exploitative conditions, and the marginalised or vulnerable groups. However, it is not without challenges and criticisms (Kindon *et al.*, 2010, p. 1). The term 'challenges' better captures the circumstances as a reminder of something to be recognised and anticipated, rather than the terms 'weakness or limitation', which may carry negative connotations and be discouraging.

This section is in no way an exhaustive description of the broad literature on the challenges and criticisms of PAR. However, this section lists the most common issues mentioned by those who have previously undertaken PAR in a PhD:

- *PAR is time-consuming, and demanding* (Klocker, 2012, p. 153; Maguire, 1987, p.198).

This is the most commonly experienced challenge as "building trust take time"... "participants resume their regular life activities, while researchers may be able to invest their total time in the participatory research project" (Maguire, 1987, p.198) We are not always able to accurately estimate the time required for the participant to participate in the research process.

However, the literature - especially that relating to PAR PhDs has revealed that this challenge can be tackled. Many authors using PAR were able to complete their research degree and graduated (Klocker, 2012; Maguire, 1987; Ollerston & Hosfall, 2013; Radermacher, 2006; Read, 2012; Valade, 2004) as seen in the following quote:

PAR PhDs are inherently *do-able*...My own thesis was submitted... before the action component of the project had reached a firm conclusion. Although this initially caused me concern, I learned that it is possible for me to write a thesis without a 'neat' ending to the PAR process. It was acceptable for me to note the factors beyond my control, and to draw attention to my continued engagement in the action process beyond thesis submission (Klocker, 2012, p.154)

- PAR is a collaborative process. This statement commonly leads to the perception that collaboration or collective action by participants must happened at **all stages** of the PAR process, otherwise it is judged as weak, false and unreliable, untrustworthy, unfruitful and disappointing (Klocker, 2012, p.152).

However, there is general agreement that it is the 'ideal' but rare in reality (Kindon *et al.*, 2010, p. 15; Kidd & Krall, 2005, p. 188, Klocker, 2012, p. 157). It is more realistic, in this case, to acknowledge that there are degrees of participation based on a non-hierarchical participation framework. This study concurred with the six **degrees of participant involvement in PAR**, which emphasising that "each form of participation can be regarded in its own right, with its own unique set of characteristics, with the type of participation that a person is engaged with being dependent upon the context" (Radermacher, 2006, p.27). An illustration of this degree of participation is displayed in Figure 3.2.

- PAR "sometimes glossy (or glossed-over) presentation" (Pain, 2004 in Klocker, 2012, p.158) in that it has to be initiated based on research problem originating in a group affected by that problem(s) (Maguire, 1987, p.43; Klocker, 2012, p.153).

In reality, marginalised individuals rarely articulate their 'feelings' about problems requiring attention or investigation. As a consequence, they are rarely found within 'readily-form groups' that initiate research to better their lives (Maguire, 1987, p.44; Klocker, 2012, p.153). Therefore, PAR is more likely to be initiated by outside researchers who have access to financial and

institutional resources, who have the commitment, skills and the ability to set up and facilitate a PAR (Maguire, 1987, p.43).

- PAR has been criticised as not being scholarly study, and ‘insufficiently theoretical’, to make a valid and valuable contribution to academic knowledge due to local knowledge produced by the collaborative work of PAR (Klocker, 2012, p.154).

Klocker does not deny this fact, but argues that “there are still some academics whose definitions of legitimate academic writing remain limited to disembodied ‘high theory’, but they are (in my experience) increasingly in the minority” (2012, p.155).

3.1.6. Previous scholarly studies relating to application of PAR

PAR has been applied in a range of different settings and contexts worldwide, but all are based on real problems experienced by the people affected by them and have made relevant and significant contributions. Due to its widespread use, this section is in no way exhaustive. However, this section presents a variety of studies which applied PAR that are considered valuable for the present study. These reviews are organised into four subsections: First, various applications of PAR; second, PAR related with disability issues and PWD; third, PAR and PhD research; and finally, PAR with video.

a. Various applications of PAR

Applications of PAR in the following setting were illustrated by Selener (1997) who mentioned that it has been employed in community development settings in India among indigenous farmers who were struggling to retain the use of their forests and land (p.44). It has also been applied and takes on an important role in large electronic corporations to solve serious problems involving work-related injuries (p 86); in educational settings in Yolo County, California, this approach has been implemented to help teachers solve problems in their classrooms with both curriculum improvement and in-service education (p.135). Furthermore, PAR has been deployed to help small, resource-poor

upland farmers in Eastern Visayas, the Philippines to improve cropping patterns (p. 185).

There has been widespread application of PAR for research in educational contexts and practices. The literature dedicated to this application has appeared widely in educational action research journals, and has been championed by scholars such as Stephen Kemmis (2006) and Robin McTaggart (1991; 2006; 2007).

The literature on PAR for health-related issues is also prominent, and while the following examples are not exhaustive, they have common characteristics, namely being associated with people facing significant health issues, and engagement with small numbers of participants. The first example involved PAR with 13 older adults with chronic pain experience in Michigan-the United States. This study used the photo voice method to understand how chronic pain impacted participants' lives in order to provide appropriate services to ageing populations (Baker & Wang, 2006). The second example was PAR conducted on six Ugandan nurses during the provision of care for patients with AIDS in Uganda, Africa, to highlight the many challenges and opportunities to transform nursing practice and create institutional change (Fournier, Mill, Kipp, & Walusimbi, 2007). This study was part of the first author's Master's thesis conducted over approximately nine months in Kampala, Uganda. The third example was PAR with 11 people living with the chronic illness End-Stage Renal Disease (ESRD) in Montreal, Quebec, Canada (Allen & Hutchinson, 2009). This study also used photovoice methods and documentary filmmaking to address the challenges faced by people with ESRD in order to improve their lives and to build a public awareness campaign regarding kidney disease.

Another interesting example of a non-health related application of PAR with a small number of participants, was a study of three child domestic workers who experienced exploitation and abuse in the Iringa municipality of Tanzania. This study intended to improve their lives by drafting a contract and supporting by-

laws to regulate child domestic work in Iringa (Klocker, 2011; 2012). This research was part of the author's PhD thesis.

However, there are also examples of PAR with a larger number of participants. The first was a PAR project funded by the Canadian Government and conducted by academic researchers at the University of Windsor with 25 South Asian immigrant women in Montreal, Canada. It contributed to empowerment and social justice related to balancing work and family for its participants (Cassano & Dunlop, 2005). The second example was PAR with 82 people from five rural, tribal villages in Gujarat, India, to explain community perceptions of health issues (Read, 2012). This study was part of the author's PhD thesis, and the researcher received funding from the Centre for Advanced Studies in Asia, Australia and the Pacific (CASAAP). It was a collaborative study with the Center for Rural Development (CRD), the Research Center for Women's Studies (RCWS), and SNDT Women's University in Mumbai, India. The third example is a case of PAR engaging 100 women who were asylum seekers and refugees in Scotland who had experienced human rights abuses or had come from conflict areas such as Somalia, Eritrea, Pakistan, Iran, Iraq, Sri Lanka and China, to provide appropriate services for them (Quinn, 2013). This programme and study was based upon the earlier Mosaics programme with settled ethnic minority communities in Scotland.

b. PAR relating to disability issues and PWD

There has been a growth in the number of PAR projects, even though not all of them were termed PAR. This appeared to be closely related to the disability movement from which the Social Model of disability emerged, as described in Chapter 2. However, a significant growth in publications has been related to cognitive disability, such as people with mental health problems (Parr, 2007), mental retardation (Valade, 2004), developmental disabilities (Sample, 1996), intellectual disabilities (Schormans, 2010) or learning disabilities (Ollerton & Horsfall, 2013).

Walmsley was one of the pioneers in this field, who coined the term “inclusive research” to confirm that this type of PAR enables people with intellectual disability to be involved as active participants, partners or colleagues (Walmsley & Kelley, 2003). Thus, inclusive research embraces a range of research approaches that have traditionally been termed ‘participatory’, ‘action’, or ‘emancipatory’ research. Another innovator who is also a productive researcher on PAR and mental health is Yoland Wadsworth (1992, 1994, 1998 and 2001). Over eight years she has conducted PAR projects with the patients and staff of a psychiatric hospital in Melbourne, Australia. Reports of her projects have given valuable insights into how to collaborate with people who will benefit from the research from within an institution or field that seems rigid or unable to change, such as mental health institutions.

PAR involving the direct experience and opinions of PWD grown over the years. However, there is a need to develop non-Western documentation of non-cognitive/mental disability, especially from an unexplored field of disability research, such as Indonesia. I have searched existing international academic library databases for ‘Participatory Action Research and disability in Indonesia’, but this failed to produce any PAR on disability. This seems to be linked to the fact that PAR is, in reality, being used by international organisations working within the disability sector in non-Western countries, but this experience is rarely disseminated to the academic community via international publications (Katsui & Koistinen, 2008, p.747)

Despite the lack of documentation on PAR and non-cognitive disabilities, the following examples have been found from other parts of the world. The first example is a multistage four year PAR project involving more than 2800 participants of children with severe to moderate disabilities (Beamish & Bryer, 1999). It successfully produced the best practice of early intervention through early special education in Queensland in the form of program quality indicators (PQI) for early special education. The second example is PAR with 28 adults with disabilities who were vocational service users from five regions in New Zealand (Millner & Kelly, 2009). This study resulted in the participants’

identification of five key attributes of place (self-determination, social identity, reciprocity and valued contribution, participatory expectations, and psychological safety), which are important qualitative antecedents to a sense of participatory membership and community belonging. This has created a better shared understanding of how participants can experience community participation that improves social inclusion and support for service users in vocational institutions for PWD in New Zealand.

c. PAR as PhD research

Several PhD using PAR surfaced during my literature review and during the process of writing the thesis. I have summarised them in the previous chapter namely literature review. In this section, I present them in more detail because they provided much insight for this study.

The first two journal articles were PhD studies using PAR but not in relation to disability issues nor people with disabilities as their participants. From these articles two I was learnt that PAR does not offer any particular strategy for research and is an inherently time-intensive. Learning from these two studies, I discovered that the timeframe and budget are issues to be aware of when contemplating the use of PAR. These two publications were written by Australian PhD candidates (Klocker, 2011; Read, 2012) who were unable to complete their PAR projects within the expected timeframe, but they were still able to complete their PhD theses by explaining their experiences, challenges, and the reasons behind their incomplete PAR. Natascha Klocker (2011) was an Australian student who conducted research on child labour in Tanzania, Africa, despite her inability to speak the local language. Clancy Read (2012) was an Australian who did research on community perceptions of health issues in five rural, tribal villages in Gujarat, Western India. Read was also a university student who relied on her interpreter while doing her research. Their experiences with incomplete PAR seemed closely related due to the fact that both of them were foreigners doing research in non-Western countries. This

fact brought hope that I would have an advantage, language-wise, because I would be conducting research in Indonesia, where I speak the language.

The third publication discussed two PhD PARs regarding PWD conducted by two female PhD candidates who were also PWD and involved in disability activism in Scotland and Canada (McFarlane and Hansen, 2010, p.88). Hazel McFarlane conducted PAR with 27 women resident in Glasgow and Edinburgh, Scotland to study disabled women and social-spatial barriers to motherhood. Nancy E Hansen examined disabled women's access to employment with 20 women in Scotland and 20 women in Ottawa, Canada. A 'collective outcome of their PAR, as expressed by their participants, was developing a drama production based on their experience. The participants themselves initiated it, then actively participated in writing the script and the production (McFarlane and Hansen, 2010, p.93). This publication has inspired and assisted me in understanding at least two ideas related to a PAR PhD. First, I learnt that it is possible and scholarly acceptable to use PAR in relation to social barriers for PWD, that is McFarlane focused on hostility in the reproductive arena and Hansen focused on employment. Second, I discovered that it was also possible and acceptable to carry out the 'action' part of PAR in the form of audio-visual media which in this study, was a drama play. Accordingly, the play was inseparable from PAR as a scientific study.

The fourth publication was a PhD study employing PAR with PWD who were members of the Disability Justice Advocacy (DJA) - a DPO that provides individual advocacy to people with high support needs associated with a physical disability in Melbourne, Australia (Radermacher, 2006, 2010). Radermacher was an Australian student who conducted PAR to explain the experiences of the participants involved in the process of developing a strategic plan for DJA, both from the perspective of the participants (six board and six staff members) and herself, as the researcher. From her thesis, I learnt that: "even in an organisation that is specifically attuned to meeting the needs of disabled people, there is still considerable exclusion and institutional

discrimination”. It gave me an insight into how to conduct PAR with PWD underpinned by the Social Model of Disability, the terms ‘ableism’ and ‘disablism’, and the illustration of the degree of participant involvement. Her research revealed that underlying ableist attitudes (i.e. attitudes based on non-disabled standards) reinforce the ongoing victimisation and oppression experienced by PWD.

The fifth publication presented the challenges of two PhD candidates from Finland using PAR in non-Western countries on disability issues and PWD as their participants (Katsui & Koistinen, 2008). Hisayo Katsui’s PhD PAR focused on the establishment of the disability movement in Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan in collaboration with DPO in Finland and those five central Asia countries. Mari Koistinen framed her PhD PAR around the experience of vocational training and employment of people with learning disabilities in Zambia, Africa. They concluded that there were at least five challenges to apply PAR with people with disabilities in non-Western context for their PhD. These are: difficulties in finding funding; ownership and control of PhD programmes; accessibility; participation; and research outcomes. They responded to these challenges through cultural sensitivity; a diverse level of participation; and realistic research goal.

The sixth publication was a PhD PAR with five people with learning disabilities in New South Wales, Australia (Ollerton & Horsfall, 2013). Janice Ollerton was a PhD student and Debby Horsfall, her research supervisor, who aimed her PAR at five people, aged 18–23 years old and labelled with mild-moderate learning difficulties, who self-referred and voluntarily joined the research team (p. 621). This study demonstrated how the CRPD was operationalised using photovoice to facilitate the participation of young people with learning disabilities in the research process, to dialogically unpack the barriers, to mediate the operationalisation of the CRPD, to analyze findings, and to promote social change in terms of removing barriers to their rights. Photo-voice was used as a key research tool “as it does not presume the ability to read or

write, and place emphasis on action over cognition so that abstract concepts can be captured as images and made concrete” (p.621). This study underpinned by the Social Model of disability, comprised a deliberate melding of Wamsley’s inclusive research and McTaggart’s PAR. This combination approach referred to as inclusive participatory action research (IPAR) functioned as “a means by which the right to rights could be expressed, explored, claimed and gained by the research team”. This study also informed me that this approach “permits non-disabled researchers to identify a research problem and bring it to the community of people labelled with learning difficulties to see whether they consider it worthy of investigation”, and as a consequence, the research topic is owned, although not necessarily initiated, by the inclusive research team (Walmsley and Johnson 2003 cited by Ollerton, 2013, p.620). This study concluded that the implementation of IPAR using photo-voice was a useful, effective and accessible means of operationalising the CRPD for co-researchers to claim their disability rights, identify them, communicate them and demand action when rights are ignored or contravened. The team realised that awareness-raising and fostering respect for rights and dignity is everyone’s responsibility (Article 8.1a of the CRPD). It prompted them to actively disseminate and generate ‘public awareness’ through:

- Providing input to the Disability Standards for Accessible Public Transport to various agents, such as the New South Wales Minister for Transport; the Australian Disability Commissioner, the Independent Living Centre’s Access Awareness’ programme, with positive responses (p.626);
- A research project website (Penrith Photo-voice Project 2010), conference co-presentations, journal articles and joint-lectures, and co-presentation to education professionals, schools and disability services (p.627).

The seventh publication is a PhD PAR with American adults with mental retardation in Louisville, Kentucky, the US (Valade, 2004). Rita Maria Valade is a Catholic nun who is also a Social Worker and a PhD student at the University of Louisville. She conducted this PAR “to offer a correction on the

absence of mental retardation research on the Social Work profession” and offer people with mental retardation a vehicle for their opinions, actions and voices. I was inspired by the way she arranged and presented her dissertation. She used videotapes to report each session of her research and highlighted the experience of research participants. For this, she was assisted by a videographer, and a local video editing service to edit and compile all her PAR videotapes into one final video. Moreover, the research participants expressed pride in their involvement and desired recognition via making their identities public in the dissertation and video. This meant they asked Rita to decline the anonymity previously stated in their signed consent forms as an ethics requirement. This 10-month research project revealed that PAR is feasible, for people with mental retardation to act as co-researchers because in this study they successfully held group gatherings and meetings with the director of the paratransit system in Louisville to discuss their questions and concerns.

All of these PAR PhD publications gave me valuable insights and encouragement, but there were limitations due to the fact that:

- Most of these studies were carried out in a Western context (except Katsui & Koistinen (2008) who carried out PAR in non-Western regions: Central Asia and Zambia, Africa),
- Most of these studies did not specifically discuss disability awareness raising strategies, except Ollerton’s PhD PAR (2013) which within the ‘action’ part of the study included Australian people with learning disabilities. Two other publications can be regarded as discussing disability awareness raising strategies: the PhD PAR of McFarlane and Hansen (2010), which involved a drama production by their research participants, who were disabled women in Scotland and Canada; and Valade’s dissertation (2004) , which generated a video to record her PAR PhD process with American adults with mental retardation.

It was a challenge for me to transfer their insights and research experiences to a very different context such as Indonesia. On the other hand, it also meant

that there was a research gap that provided the opportunity for my original contribution to this field.

d. PAR with video

This study was informed by three research publications about PAR with video. These publications inspired and assisted me to understand that it is possible and scholarly acceptable to do PAR that:

- 1) Is not initiated by members of a marginalised group whom I intended to collaborate with them as research participants or co-researchers.
- 2) Produces a video/film as collaborative action with participants. This, in fact, is a mandatory requirement, which is embedded in 'participatory **action** research'. Therefore, a video production is not a form of intervention, but an integral part of this research.

The first publication was PAR where its 'action stage' collaboratively produced a public education video as an awareness raising strategy about Social Work at the University of Ghana, West Africa (Kreitzer *et al.*, 2009). The second study reported participatory video with members of Maori tribe in the lower North island in New Zealand (Hume-Cook *et al.*, 2010); the third study was a journal article demonstrating a film-making process using PAR in Scotland (Parr, H, 2007). The following description will present more detail on each of these study.

I was grateful when I found the first publication in an international journal on social work education about the application of PAR in a non-Western context, namely Africa. (Kreitzer, et.al, 2009). The first author was a Canadian social worker who was also lecturer and researcher at the University of Calgary, Canada, who was invited to work at the University of Ghana, Legon, Africa. This PAR investigated culturally appropriate training and practice in social work education in Ghana. It was, not about disability or PWD but it had the same background of social work and had the same objective of seeking to

understand and explore culturally appropriate practice procedures against the importation of Western knowledge. This study provided a creative and empowering environment where faculty, students, social workers and a community leader finally decided on five action plan for their social work education and practice. For me, the two most interesting and important results from these action plans were the use of audio-visual equipment and video production: 'One of the recommendations was that the department should invest in audio-visual equipment for use as a teaching tool' (p. 159).

We agreed to produce a public education video on social work in Ghana. The script was written and collated by everyone. Ghana TV was hired to make the video, which included video-taping group members in their own social work setting. After the completion of the video, the group edited it and a final copy was made to be shown on TV. Each group member plus the department of social work were given copies. The video was a way for the group members to participate in a practical educational activity and to show their own work and skills as social workers (Kreitzer *et al*, 2009, pp. 159-160).

Kreitzer initiated this PAR with a research topic that reflected her own interests or concerns but then confirmed that these had been understood by participants as their own issues and problems. Finally, they agreed to 'bring about change' by collaboratively producing a public education video as an awareness-raising strategy about Social Work in Ghana, with professional video-making technical support from Ghana TV's crews.

However, there were limitations to this study as it did not directly discuss disability issues nor did it involve the participation of PWD. It was also not PhD research. Despite this, it encouraged me to explore the use of video as a culturally appropriate awareness-raising strategy in a non-Western context.

The second study (Hume-Cook *et al.*, 2010) was a collaborative research initiated by Sara Kindon when she was granted a university-funded project using PAR and video to explore the relationship between place, identity and social cohesion within remote rural communities in Aotearoa/New Zealand by, with and for a Maori tribe in the lower North Island. This study informed me that PAR with video is a well-known methodology and method of research:

Participatory research using video first occurred on Fogo Island, Canada in the late 1960s as a tool to document social problems for social change, and to use the audio-visual process to raise awareness and share information within and beyond the community involved. It was facilitating research participants who became 'meaning makers' who explored and worked to change their own realities through production and analysis of video products. (Hume-Cook *et al.*, 2010, p.161).

Further, this research demonstrated that there are at least three primary outcomes of participatory videos: first, the interaction of individuals and their personal growth which occurs during the production process; second, the sense of community and cooperation involved in making a video; and third, the ability to influence decisions affecting the lives of those who are involved in the process of making a video (p. 162). There was also specific personal expression with regard to these outcomes:

We are proud... We have an archive of audio-visual materials about the relationship between place, identity and social cohesion within *Ngāti Hauiti* at the turn of the millennium. This serves as a valuable resource for future generations and for our ongoing collaboration (p. 166).

Thus, I learned from this expression that **the video** was considered by all participants and researchers **not as peripheral end product of their**

Participatory Action Research, but as an integral component of the research itself.

This study also informed me that there are at least two sources of agreement in the area of participatory video:

- 1) At the heart of participatory video is the commitment that participants create videos according to their own priorities; they - not outsider video producer - control how they are represented and they decide what the video will be used for (p.162).
- 2) Stages of the video production process can last between a few days to several years depending on the purpose of the initiative, the degree of social change desired, the level of funding, and the nature of the relationship between the outside researchers and/or video producers and community members.(p.162)

The main limitations were that this study was done in a Western context; it did not directly discuss disability issues nor work with PWD; and it was not a PhD study. Despite this, this study has deeply enlightened me as I was intending to do PAR on disability awareness issues in Indonesia due to the unavailability of audio-visual instruments. This was especially the case as I had no previous experience with regard to both PAR and the use of audio-visual instruments as a disability awareness-raising strategy. This 'enlightenment' was attained through important detailed information about ten typical stages in the participatory video process (p. 162), and the lessons learned from working with participatory video. The first lesson especially convinced me of the possibility of doing collaborative research using participative video, 'even if you're not an experienced video producer or academic researcher' (Hume-Cook *et al.*, 2010, p. 168).

The third study that inspired and assisted me with understanding the research rigour required for PAR with video was a research report from Hester Parr (2007), who is an academic at the Department of Geography at the University

of Dundee. Parr works on health and disability and innovative participative methodologies. She reported in detail on her experience with film-making using PAR. She was primarily concerned with revealing that the film-making process can act as a text that holds valuable data about the impact of arts on mental health. It is also as a method, and a way of knowing and reading artistic spaces of wellbeing for a particular group/research participants. This report also explained that video-making has a long history as a visual method of research in disciplines such as sociology, anthropology, ethnomethodological studies and cultural studies.

Parr's report describes 12 months of film-making which produced a 30-minute film entitled *Recovering Lives*, which features four community mental health projects in three different cities in Scotland that engage arts and gardening work to help people with severe mental health problems to live meaningful everyday lives (Parr, 2010, p. 118).

From the way she arranged this report, I learnt that there are four phases of the film-making process: the planning and negotiation of roles; the filming itself; the editing process; and finally the showing and dissemination of the film. This also informed me that throughout these phases, film-making can offer ways for social distance, expertise, and authority to be disrupted or negotiated, and also how mutual benefit can be achieved in ways that try to avoid practices of top-down empowerment. In other words, this report is about the social inclusion of people with disabilities, especially people with mental health problems.

Furthermore, I was made aware that there is a difference between Parr's four phases of film-making and Hume-Cook's ten stages of video-making. Hume-Cook does not mention the editing process as one of their stages. It is an interesting contrast as Hume-Cook is an independent Australian audio-video producer based in Wellington, New Zealand, while Parr is an academic in Dundee Scotland who 'had no previous experience of film-making' (Parr, 2007, p. 118) nor 'editing film' (p. 125). Despite this, Parr found that the editing

process was 'an effective methodological medium through which collaborative meanings and understandings of mental health were emergent' (p. 126). Besides this, in the editing process (which included 'moving through the selected frames, accepting and declining certain images, voice-overs and interviews) 'we were actively negotiating our visioning and understanding of social inclusion and mental health in practice, something LUNA² had felt unable to articulate previously".

This study reported that one of the important results from this film making process:

- for the research participants was that they:
 - explicitly recognised their role in co-empowerment, actively seeking to reinforce the notion that people with mental health problems are not passive in collaborative relationships, but rather can be seen as powerful actors with skills and capacities that might translate across (supposed) knowledge barriers (2010, p.129).
- for Hester Parr as initiator of this study, PAR made her research "more accessible and relevant to a wider audience, emphasising the mutual effectiveness of academic-film-making partnerships" (2010, p. 129).

This collaborative film-making informed me of six important conclusions:

- 1) Collaborative film-making between academics and community film-makers is not a straightforward process, nor easy to manage or predict in terms of concerns about equality and dominance.
- 2) There are multiple processes of film-making relating to film-making practice, production and managerial articulations of film, through which powerful hierarchies can emerge from and between different actors.

² LUNA is the mental health and arts group in Dundee, Scotland that was one of research participants in this research project which Hester Parr collaborated with.

- 3) It is nonetheless recognisable for its value in 'breaking down barriers', which can be simultaneously social, psychological, professional and material.
- 4) The process of film-making has been at least as important as the product of this collaborative project, if not more so.
- 5) Film-making facilitates a way of sharing in and understanding the multiple ways in which creative work shapes senses of self-esteem and purpose for those who partake, but also for those who perhaps find it difficult (initially) to articulate such benefits.
- 6) The film-making process and its products act as a fascinating text through which it is possible to read the making of these benefits and politics, and also critique the working of cross-community participatory relationships. (Parr, 2010, p.130-131)

From Parr's report, I also learnt that the term film and video are commonly used interchangeably, despite there being technical and cultural distinctions between them. Technically, film is related to the product of film-making or video-making in the format that can only be played in a film player and shown in the cinema or movie theatre (Parr, 2010, p. 132). In contrast, a video can be played in a video player even on a personal computer, laptop or notebook that is equipped with compact disc (CD) or digital video disc (DVD) player.

This is the end of section of the Chapter which has highlighted a number of significant aspects of PAR as principal research methodology of this study. The next section presents research methods applied in this study.

3.2 RESEARCH METHODS

This study involved qualitative research within a PAR framework. While PAR has been described as both a quantitative and qualitative approach, I believe that PAR is qualitative by nature, considering that it is concerned with people's experiences and that they are referred to as active collaborators and treated as experts on their experiences (Minichiello & Kottler, 2010, pp.18-19). PAR is

concerned with generating knowledge through interaction and dialogue (Brydon-Miller, Kral, Maguire, Noffke & Sabhlok, 2011, p.390; Reason, 1998, p. 270) which is not easily acquired through non-qualitative research approaches. This study sees qualitative research as being defined as:

A situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of meaning people bring to them (Denzin & Lincoln, 2011, p. 3)

This study understands the process of qualitative research as being described as:

Begins with an assumption and the use of an interpretive/theoretical framework that inform the study of research problem addressing the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researchers, a complex description and interpretation of the problem and its contribution to the literature or a call for change (Cresswell, 2013, p. 44).

Although PAR is a methodology that emphasises collaboration with participants, yet as the initiating researcher and as an integral part of the academic requirements of a PhD, it is necessary to outline what I planned and did in this study. There is no agreed upon structure for how to design a

qualitative study (Creswell, 2013, p.49), nor PAR (Kemmis & McTaggart, 2008, p.276), There are only general suggestions. Following suggestions that have been summarized by Creswell (2013, p.61-64), this section describes the research sampling techniques, the data collection method, the method of data analysis/interpretation of findings, the study's rigour, and ethical issues.

3.2.1 Research sampling and recruitment

3.2.1.1. Research sampling

Taking the background, questions and objectives of this study into consideration, this study uses purposive sampling (Alston & Bowles, 2003, p. 89; Neuman, 2007, p. 142; Neuman, 2009, p. 91). This refer to "selected "individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study" (Cresswell, 2013, p. 156). This sampling was chosen as this study recruited participants purposefully - following Wadsworth and Epstein's criteria for participatory change (2001, p. 8). As such, the participants were Indonesian PWD who had lived experience related to the phenomenon being studied (disability awareness), and they were able to identify discrepancies between how things are and how they could or should be, and believe things *should* and *could* be changed as regards disability awareness in Indonesia. Details of this are described in the following section on the participants.

I had considered the statement that PAR acknowledges and encourages the recruitment of participants via familiar resources and persons with whom a relationship already existed (Valade, 2004, p. 75). Accordingly, this study recruited participants with information and referrals from the Disability Studies Centre of the University of Indonesia (DSC-UI), an institution that I was familiar with and considered would be a perfect entry into obtaining participants who fit with the purpose of this PAR. Correspondingly, this study's recruitment of participants was processed via the DSC-UI. I requested the DSC-UI to identify possible appropriate participants who matched the inclusion criteria of this research.

3.2.1.2. Participants recruitment

With regard to participants, a Critical Reference Group (CRG) was a central to this PAR. Wadsworth (1993, p.5-6; 1997) promotes the idea of setting up a CRG as a group of “the researched for” – in the sense of addressing the problem the research sets out to resolve. A CRG is a group of informed people that guide the PAR. These people typically have intimate knowledge and lived experience of the issue or problem being researched and a commitment to the research bringing about social change. The roles played by members of a CRG include being **co-researchers and collaborators that provide expertise, guidance, and dialogue** to this study.

In this study, the CRG was recruited purposively with the following inclusion criteria which was guided by Wadsworth and Epstein’s criteria for **participatory change** (2001, p.8):

- Indonesian people with disabilities;
- Above 30 years old;
- Having personal experience related to disability awareness in Indonesia and have studied overseas with international scholarship facilities;
- Be activist members in Indonesian Non-Government Organizations (NGOs) for people with disabilities. Internationally, such NGOs are often referred to as disabled people’s organisations (DPOs).

Pertaining to age, the preliminary information suggested it would be difficult to find Indonesian PWD who had studied at universities abroad and were also below 30 years of age. On average, due to a variety of circumstances, it takes longer for Indonesian people with disabilities to access education opportunities, especially at international tertiary institutions.

As to the criterion of being ‘activist’ member of a DPO, this study emphasised that this was only an entry point or bridge for referrals, as potential PWDs participated as individuals not as affiliates or representatives of particular organisations or DPOs. This was intended to prevent the possibility of the

individuals acting according to hidden interests on behalf of their group. I was informed of this risk by a report on a PAR project to uncover important aspects of the social context of women's lives among African-American women. This project established a community advisory board (CAG), which recruited from community organisations, unions, and service organisations. Participants, however, were required to participate as individuals -not as representatives of their organisations (Mulling *et al.*, 2001, p. 87).

The inclusion criteria was based on the assumption that such participants would have experiential knowledge of disability discourse and disability awareness, both in Indonesia and in the countries in which they had lived during their studies, so that they would be capable to express analytical and factual arguments in order to make crucial and important changes.

Accordingly, it can be assumed that PWD who would fit with all those criteria are those from middle and upper classes of society. This may be true but I prefer to argue that middle or upper class people should not be seen as automatically identical to those who come from the rich or 'the haves' sector of society, who have capital or special privileges. Instead, it is more related to those who have strong beliefs, courage, ability and commitment. The DSC-UI was initiated and driven by a few Indonesian PWD with such criteria who had the courage to start their centre without any material resources. Yet they did have the ability to identify discrepancies in disability awareness in Indonesia, and shared a commitment to the belief that disability awareness in Indonesia should and could be changed. It was very clear that they had a strong belief in the need for change which is a condition for participatory transformation (Wadsworth & Epstein, 2001, p.8).

However, I also realised that these inclusion criteria might eliminate the possibility of many Indonesian PWD becoming participants, who would be able to give critical and objective thought, arguments and ideas, and help bring about change more significantly. It was an uneasy decision, but it was the best I could do given the real and inflexible limitations of time and resources. This

was related to the fact that this study was part of an academic requirement to complete my study in Australia with sponsorship from my home country with limited time and a tight budget.

With regard to sample size, I decided to recruit approximately 10 CRG participants, which is an appropriate and common number for qualitative research (Cresswell, 2013, p. 157, Morse, 2000, p. 5; Padget, 2008, p. 56; Smith, 2009, p. 52). Overall, as Smith has emphasized numbers will be limited by issues of time, reflection and dialogue for successful in-depth analysis (2009, p. 52).

The CRG participants were recruited after I had received details and referrals from the DSC-UI of 15 persons fitting my inclusion criteria. In September 2010, I contacted each potential participant via phone and emailed them to brief them on the proposed research and invited them to participate. I provided them with participant CRG information and informed consent sheets. Ten participants, comprising of five males and five females and aged between 30–60 years old, accepted my invitation, signed the consent form and became the CRG for this study. I did not intentionally set out to balance gender due to an unpredictable population, so I was satisfied when I achieved a balanced gender representation.

Further description within regard to the CRG members and additional participants in this PAR will be described in Chapter Four.

The need for additional participants arose later, which was after the observation and reflection on the actions linked to the first and second objectives, which prompted the decision to produce a video for the third objective of this PAR. Additional participants were needed to play roles in the video (referred to as video participants). The CRG and I then realized that we also needed another additional participants who acted as information enrichers for the editing stage of the video making process (also referred to as editing participants). This editing participants comprised a group of Indonesians lived

experience of disabilities who were members of a DPO and a group of undergraduate students from state and private universities in Jakarta. The rationale of the first groups' recruitment was to allow more Indonesian people with lived experience of disabilities to share their knowledge, needs, interests and aspirations. The second group was recruited to allow information from representation of the intended target audience. This is discussed in more detail in the next chapter in the target audience section.

The inclusion criteria, recruitment and numbers were generated through collaboration with the CRG participants. Due to unexpected incidents that will be addressed later in the research process section, the CRG and I decided to set flexible inclusion criteria for these additional participants as follows:

- Above 17 years old
- An active member of a DPO and
- An active undergraduate student (not on leave of absence) for students' group

The assumption underpinning these criteria was that participants would be able to express opinions independently, and their activeness would facilitate the recruitment process in limited time. The CRG members played an active role in the recruitment of the participants. Participants were recruited from DPOs and universities that had contacts with a CRG member. This was very helpful to optimize the preparation of the research process activity within a limited time and budget.

- Recruitment of video participants

Because of their extensive experience and relationships with many Indonesian PWD, the CRG members played an active role in the recruitment of these participants. One of the CRG members contacted each potential participant via phone and direct conversation to invite them to participate in this research project and explained the details and the timeframe for the video shooting.

- Recruitment of DPO member participants

The CRG members personally communicated with contacts in the DPO of visual impairment, the DPO of hearing impairment, and the DPO of wheelchair users, which are located in Jakarta, to inform them of our plan and to ask them to provide ten active members fitting the inclusion criteria. The CRG also explaining, however, that these member would be participating as individuals with disabilities and not as representatives or on behalf of the DPOs. I followed this up with an invitation letter for participants via each DPO to explain the detailed process.

- Recruitment of undergraduate student participants

The CRG members personally communicated with contacts in a public and private university in Jakarta to inform them of our scheduled activity and to request undergraduate student participation. The way the CRG handled the recruitment, was apparently helpful to avoid the bureaucracy related to sending invitation letters to prospective participants in the universities, as there was a conflict in schedules between those universities due to their semester breaks. After negotiating with them, we agreed to modify our initial plan from only one session for undergraduate students from both universities to one session per university.

3.2.2 Data collection methods

Although PAR does not offer one particular strategy for research, there are some important features common to PAR are “their practical and direct nature, their ability to enable people to generate information and share knowledge on their own terms using their own symbols, language or art form (Kindon *et al.*, 2010, p.17).

The methods to collect data in this study were following the common methods used in qualitative research (Creswell, 2013, p.159) and in PAR which have been summarised by Kindon *et al* (2010, p.17). These include interviewing, group discussions, and media-based methods such as video.

There were three kinds of data collection from the CRG participants, which consisted of two individual interviews each and one group discussion.

In the two individual interviews, each CRG member was interviewed face-to-face or via telephone and/or email. The interviews were loosely structured by discussion points. Each interview lasted about 1-2 hours at a time convenient for each participant, and was conducted either at their workplace or home. Sometimes, interviews occurred after office hours; this was due to the fact that the participants were busy and could only volunteer their time after work. All interviews were digitally recorded and transcribed verbatim.

a. **The first individual interview** sought to gain insight into issues or themes relating to the realities of PWD life in Indonesia and the current level of disability awareness. The interviews were loosely structured by a checklist of discussion points. The first interview's list of discussion point asked the participants to describe:

- Their lived experience
- Their views on the realities of PWD life in Indonesia

As to the preparation for the second interview, I mentioned the idea of providing the CRG with selected several disability awareness videos, which I had previously downloaded from YouTube and reviewed. This was envisioned as a media-based method which would be a basis for further discussion of their thoughts and ideas in the next interview. The CRG participants approved of this idea, and even suggested including a documentary video from the DSC-UI.

b. **The second individual interview** was conducted to explore and analyse the key issues related to the current level of disability awareness (the second research objective); the CRG members' general comments/opinions on the examples of disability awareness (DA) videos; and what their thoughts and ideas were on disability awareness-raising strategies that should be developed in Indonesia and in this study.

The second interview's list of discussion points asked the participants to describe:

- Disability awareness (DA) - in general and in Indonesia.
- Any dissatisfaction with current DA programmes and materials in Indonesia.
- Their thoughts, ideas, and aspirations about developing a contextually appropriate DA programme and materials for Indonesia.
- Their opinions about the possibilities of and barriers to realising those aspirations.

The second interview involved nine CRG members and was conducted from January 5, 2011 to February 21, 2011. Further details are described in the research process section.

- c. **The group discussion** sought to develop a matrix of key issues that needed to be considered when developing a disability awareness-raising strategy. We tried to summarise the thoughts, opinions, and ideas from the first and second interviews and create a matrix that would become the basis or guideline to produce the 'action' part of this participatory **action** research.

This discussion was conducted in Jakarta on February 22, 2011 and involved four CRG members. Further details are explained in the research process section.

3.2.3. Data analysis/interpretation of findings

Qualitative data analysis was used to analyse the information from the interviews and the discussions with the all research participants. The analysis followed a process as described by Cresswell (2013, pp. 182-188) and included: First, transcribing the field notes and working with words. Second, identifying codes from the transcripts. Third, reducing codes to themes by identifying salient trends or patterns. Fourth, relating categories by noting relationships among codes/themes and then building a logical chain of evidence. Fifth, relating categories to analytic frameworks in the literature, and

finally, displaying findings. In other words, Braun & Clarke (2006, p. 87) who also describe the process as a thematic analysis, explain that it consists of grouping data into themes, then examining all cases in the study to ensure all manifestations of each theme have been accounted for and compared, and then examining how themes are interconnected.

After the interviews and discussions with the CRG members were transcribed, I listened to all the audio recordings several times to check the accuracy of the transcripts and to acquire an overall understanding of the whole data. As I read through the transcripts, I immersed myself in the details by highlighting certain pieces of information in the text using the text highlight function in Microsoft word. This helped me to identify and organise the main ideas as part of the initial coding process. The text of each transcript was read and reflected upon, and the data was then coded manually. After scrutinising the transcripts, all the highlighted key words or descriptors were extracted and organised separately to find potential categories or themes, and to examine the similarities and differences among each keyword and the entire data set. It was my intention to have another person independently code the transcripts to verify the consistency of the coding, but there was insufficient time and resources for this to transpire. Therefore, I coded and reviewed the data and identified tentative themes by myself. These tentative themes were then presented and discussed with interested CRG participants and my supervisors. This process allowed for consistency in the method but was somewhat limited in providing different perspectives from a variety of participants. After getting feedback from the CRG and my supervisors, the tentative themes were clarified into specific themes. These specific themes were then presented in the form of a matrix and discussed again with the CRG participants to gain consensus on what the CRG considered to be the main features of disability awareness and the development of disability awareness videos.

3.2.4. Rigour

With regard to the rigour, this study adopted quality criteria of qualitative research following the suggestions of Lincoln and Guba (2011), which include credibility, transferability, dependability, and confirmability (p. 296).

In addressing the credibility of the thesis, or in other words to achieve credible research findings, this study employed two strategies. Firstly, I established trust and an engaging relationship with participants through committing myself to be open, honest, transparent, and 'to act from the heart and mind' (Pain, *et al.*, 2010, p. 29). Secondly, I conducted a study that allowed for data triangulation in the form of assorted sources of information, several methods, and various participants to enable multiple perspectives to be captured and compared. A detailed description of this criteria, generated through collaboration with the CRG participants, is presented in the research process sections. Credibility was also expected to be achieved by providing a rich, detailed description of the dialogue and collaboration among the participants and myself during the research process.

Transferability, was carried out through the delivery of sufficient realistic information, and a detailed description of the research participants and the research process. Providing such a detailed description is expected to enable the reader to determine the extent to which the findings of this study can be applied or transferred to a different context because of 'shared characteristics' (Creswell, 2013, p. 252).

To achieve dependability which refers to the consistency and stability of the research findings, this study reported in details the dialogue and collaboration among the participants and myself during the research process. However, I also appreciated subjectivity and complexity among our perceptions and understanding. This was intended to comply with one of the key characteristics of PAR: "treating diverse experiences within participants as an opportunity to enrich the research (Kindon *et al.*, 2010, p. 14).

The confirmability or neutrality of this study was enabled through a personal reflexive journal where I recorded everything I did, observed and encountered throughout the research process. It includes research plan, field notes, summaries, expectations, insights, and also feeling and emotions. Presenting this journal was also intended to acknowledge the extent of the effects of researcher preconceptions and biases which actually are unavoidable to the extent that we cannot pretend that they do not exist in qualitative research (Ezzy, 2002, p. 53)

3.2.5. Ethics approval and ethical issues

This study was approved by Curtin University Human Research Ethics Committee with approval number OTSW-13-2010 (Appendix A). I also obtained a letter of support from Professor Bambang S. Laksmono, Dean of the Faculty of Social and Political Sciences, University of Indonesia (Appendix B). These approvals were accomplished prior to commencing this study, and after this study fulfilling the University's principles and standard requirements for research ethics, namely voluntary informed consent; privacy and confidentiality; an avoidance of harm. In addition, this study also included principles respect for people, beneficence and justice.

- **Informed consent**

Informed consent refers to the consent to participate in research on a voluntary basis which is not induced using any form of unjustified pressure. It was applied in this study by providing full information and informed consent sheet to all participants which informed them of all aspects of the research, including the purpose of the study, its voluntary nature, participants' right to withdraw from the research at any time without penalty, expectations for participants' contribution to the study and the assurance that no harm would come to them as a result of the information they shared during the research project. Participants were also provided with the opportunity to ask questions about the study. Once participants were satisfied with the explanations and plans of the

study, signed informed consent was obtained from each participant. In order to maintain ethical conduct throughout this research process, the participants were asked if they had any questions or issues that they would like to discuss, whether these issues would need to be negotiated or renegotiated, and they were reminded about their choice to be involved or withdraw.

- Privacy and confidentiality

Privacy and confidentiality was ensured by explaining in the informed consent sheet that names, personal details, and any identifying information collected from the research participants would be kept private and would be treated in a confidential manner within this study. Electronic versions of both written and audio data from this study were password protected, with hard data stored in locked spaces.

However, during the data collection process and especially during process of developing audiovisual media, the participants expressed their willingness for personal and identifying information to be presented. Accordingly, I have verbal agreement from the participants for their names to be used in the credit titles of the video that was produced. Although the participants did not feel anonymity was necessary, I still respected their privacy and trust in me.

Therefore, to comply with the research ethics standards, I decided not to mention the participants' names in the chapter on research findings and replaced them with initials and numbers (for example: CRG 1 refers to participant who are the Critical Research Group number one). This numbering based on sequence of the first interview with them, which then I used as each participants' identity. This decision was my attempt to incorporate the ethical principle of privacy and confidentiality within this PAR.

- Avoidance of harm

Harm was avoided by stating on the informed consent sheet that this study posed no more than a minimal risk to research participants as a result of their involvement and the information they shared during the research project.

However, there is general agreement that the ethical conduct of qualitative research, especially PAR, involves much more than following guidelines provided by institutional ethics committees (Creswell, 2013, p. 57; Ezzy, 2002, p. 51; Manzo & Brightbill, 2010, p 33). Hence, to ensure that this qualitative research is conducted ethically, I must elaborate on how the main principles of ethical qualitative ethics (respect for persons; beneficence; justice)- as informed by Manzo and Brightbill (2010, p 33) and Creswell (2013, pp.58-59) – were also conducted in this study

- **Respect for people**

This primary principle claims that ethical studies should treat people as autonomous agents who have the legal right to be informed of all aspects of research, including the risks and benefits of participating in the research. To apply this principle, before I conducted the study I contacted each potential participant to explain all aspects of the research, including: the purpose of the study, its voluntary nature, the participant's right to withdraw from the study at any time without penalty, and the expectations for the participants in the study. After inviting them to participate, I provided them with the information sheet and consent form, and I did not pressure them into signing the consent form unless they were satisfied and feeling well-informed regarding the proposed study. In the process of collecting data, this principle was implemented by emphasising empathy, honesty, transparency and a trusting relationship with the participants by discussing how the data would be used, avoiding leading questions, avoiding the chance to cheat participants and providing proper rewards for their participation and contribution.

- **Beneficence**

This principle emphasises the need to 'do no harm' and 'do good' for participants. In the research process, this principle was employed by communicating using appropriate language, avoiding conflicts of interest and anything that would harm participants, being responsive to the needs and perspectives of participants, recognising that researchers and participants are

continually in relation with one another, providing proper rewards for participants such as money for reimbursement of transportation and communication costs and providing food and drink during the data collection process, reporting multiple perspectives and profiles, avoiding disclosing only positive results, and maximising beneficial outcomes for participants, the society and humanity.

- Justice

This principle determines that research must treat people as equals, should not be exploitative and must be fair in distributing risks and benefits. This principle was applied in this study by acknowledging participants' skills, interests and worldviews, facilitating participants' self-representation during the research process and encouraging participants' ability to initiate and enact change.

Summary of chapter

This study involved qualitative research within a PAR framework. PAR is employed as the principal research approach as this study was intended as a response to the unsatisfactory conditions for social inclusion of PWD and the low level of disability awareness in Indonesian society. PAR is congruent with and promotes the inclusive spirit of the Social Model, which assigns important roles to PWD in disability research and respects them as equal, valued, capable people, and even as a source of expertise because it recognises that the lived experiences of PWD are a source of knowledge. This study employed a purposive sampling method following Wadsworth and Epstein's (2001, p. 8) criteria for participatory change. The data collection method used in this study followed the common methods used in qualitative research and in PAR. Thematic analysis, as described by Cresswell (2013, pp. 182-188) and Braun and Clarke (2006, p. 87), was used to analyse all the information gathered from interviews and discussions with the research participants. With regard to the rigour of the study, it included the quality criteria of qualitative research following the suggestions of Lincoln and Guba (2011).

CHAPTER FOUR

RESEARCH PROCESS

This chapter delineates how this study employed participatory action research (PAR). This also demonstrates how PAR's four stages of observing, reflecting, planning, and acting in this study as part of PAR's cyclical process. As mentioned in Chapter Three (Research Methodology), PAR is predominantly characterized by its cyclical research process that consists of these four stages. In accordance with PAR terminology, this study consists of these stages and multiple cycles. This chapter begins with descriptions of PAR stages and its unique implementation in this study. This is followed by description of the cyclical research process.

4.1 PAR Stages

The research process in this study follows the PAR stages and a working PAR model as formulated by Suzi Quixley (2008, p.10), a prominent figure of PAR in Australia. As described in the Chapter Three, the research process in PAR consists of four stages:

- a. Observation: describing the actual events that occur during the research process, and collecting data to help answer specific questions (research questions and/or any question that surfaces during the research process).
- b. Reflection: analysing the observations during the process of this study and developing recommended actions.
- c. Planning: planning needed changes based on recommended actions from the reflection stage.
- d. Action: mplementing the plans to achieve the desired changes (Quixley, 2008, p.10).

These stages proceed through cycles, not in a linear formation, and a PAR cyclical process can be started from any stage, the stages are interrelated, and may even may overlap" (Quixley, 2008, p. 10). This means that the cycle of research process in PAR is not a fixed pattern, for example, beginning with the planning stage and ending with reflection. So, it can begin with any stage, and

it repeated into cycles. This happened in this study as the research began with the observation stage, and reflection occurred throughout the research process. In other words, the reflection overlapped with the other stages of this study. Moreover, to complete this PAR study, stages were repeated throughout the process in three cycles.

Therefore, a description of the research process in this chapter, begins with the subheading 'reflection', and is followed by a description of the implementation PAR stages and cycles of PAR. This is how the implementation of the PAR process in this study is unique. This is consistent with Quixley's statement that PAR's iterative cycles can be complicated to demonstrate (2008, p. 9) as PAR can be fluid, flexible and idiosyncratic (Ollerton & Horsfall, 2013, p. 620).

4.1.1 REFLECTION

In this PAR, reflection is not exactly a 'stage' or a 'step'. Rather it is an ongoing and iterative process that does not end in a linear form or at a certain moment in time. As a key facilitator of the research process, ongoing reflection needs to be incorporated into all stages. This reasoning comes from the interpretation that the 'failure to critically reflect on the research process and the role of the researcher not only raises questions of the genuineness and inclusivity of participatory research projects, but also the role of the research in the maintenance and perpetuation of the oppression of people with disabilities' (Bigby & Frawley, 2010, p. 53; Vernon, 1997, p.158).

The research process is integral to the proposed outcomes or results; therefore, the difference between what was planned for this study and what actually occurred is as important as the final action or insight. This means that the process does not follow a certain fixed pattern, and the phases can overlap. So, my understanding was that the reflection can be carried out throughout the research process. Thus, I took note of everything that I did, observed and encountered throughout the research process in my personal research journal. This journal provided me with the opportunity to integrate reflexivity (Guillemin

& Gillam, 2004, p.273; Kindon *et al.*, 2010, p.13) into the research, which in turn enabled me to identify key issues and their implications for the research process as my reflections evolved during the process. Throughout the cycles of this PAR, these reflections will be presented in boxes as follows:

Reflection Box 4.1 Example and explanation of reflections

My intention is to present reflections that are directly quoted from my research journal, in the 'reflection boxes' such as this one. I have seen this used effectively in other theses (i.e. Radermacher, 2006) as a way of clearly identify the researcher's reflection process as it emerged throughout the research.

Reflection boxes offer explanations on what issues actually happened in the research process, what worked and what did not, how the issues were handled and also what I learnt. This was a helpful addition and provided more insight and life into the research process. Yet, I felt I was a novice of Participatory Action Researcher, obsessively questioning: Can I really do this?

I found a quote from a pioneer of PAR that gave me encouragement to present my reflections in such reflection boxes throughout the process of this PAR project. The quote from Rajesh Tandon said that "Participatory action research principles are not purist. Waiting and wanting to do it right is paralysing" (Tandon cited by Maguire, 1987, p.127).

Furthermore, based on a critical reflection during the ongoing research process, a decision was made to repeat the PAR stages in three cycles. Thus, the study did not intentionally determined from the beginning of the research process that we wouldl repeat the PAR stages in three cycles. A detailed explanation of this, will be described in the following sections.

Figure 4.1 presents a simplified illustration of the three research cycles of this study. This is offered as an introduction before a detailed description of each cycle is provided.

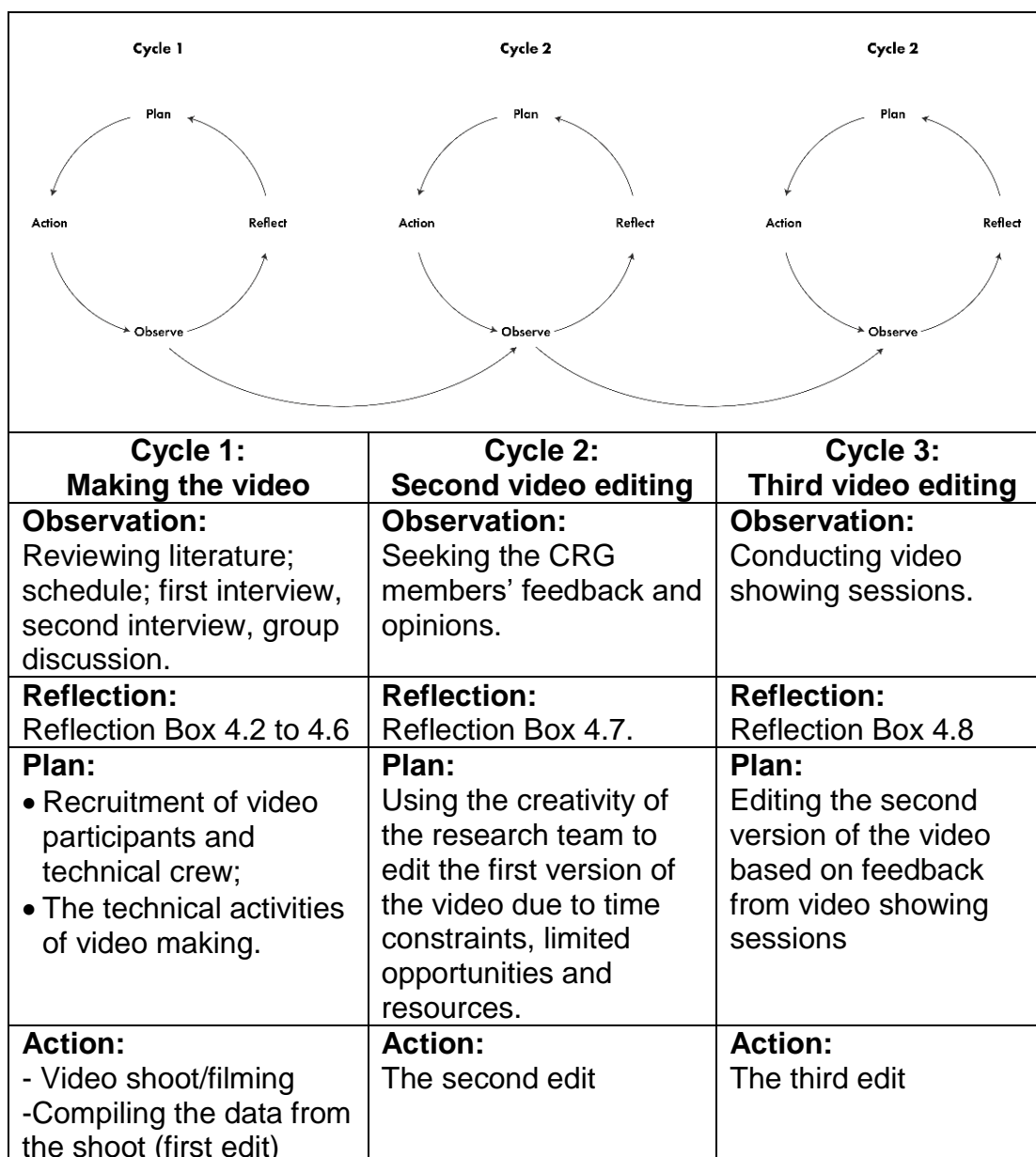


Figure 4.1. Three research cycles (PAR stages) of this study

CYCLE ONE: The video making

As illustrated in Figure 4.1, this section presents a detailed description of the first cycle of this PAR study. Cycle one comprised a full implementation of the four PAR stages. This cycle culminated in the action stage, which is the essential stage of video making: filming the participants' activities, opinions and aspirations. Therefore cycle one is named 'the video making.

4.2.1 The observation stage of the video making cycle

At the commencement of the study, I made a number of key decisions on various issues. In the previous chapter, have been described decisions on three issues, namely the research approach to be employed, the research participants to be recruited, and the ethics application which needed to be applied to the Institutional Research Ethics Committee. This observation stage covers description of the four issues: the literature review; the schedule of this PAR; the in-depth individual interviews; and the group discussion with participants.

a. Reviewing the Literature

The decision to review written materials on disability awareness issues in both international and Indonesian contexts was crucial to this stage. This literature review was aimed at locating information and references that would give me a clearer idea about how to approach the proposed research before I commenced the project with the research participants. The purpose of a literature review is to carefully identify existing research related to a field of study and position my research as an original contribution to this area.

For my research, I used library databases such as Taylor & Francis online, Routledge Taylor & Francis group, Wiley online journals, Proquest and internet-based search engines such as Google Scholar. The following key words were used for my search: 'social inclusion', 'attitudes toward people with disabilities', 'disability awareness' and 'participatory action research in disability issues'. I also tried to narrow down the search by adding the keywords 'in Indonesia' but this failed to produce any results. I discovered that very little documentation of disability in Indonesia has reached the academic community at an international level or in international publications.

I also often reviewed the references of relevant journal articles and conducted an internet search using the details available in these articles. I also managed to find some references that touched upon Indonesian literature related to disability and Indonesian people with disabilities, such as blogs written by, and

online news written about, Indonesian people with disabilities. Relevant articles were carefully selected and have been presented in earlier chapters and sections. From this, I was confident in employing PAR as my principal research approach, as I have described in the Chapter Three. In this section, I will complement these descriptions with my observations and reflection, as presented in Reflection Box 4.2.

Reflection Box 4.2 Benefits of employing PAR

PAR offers advantages to both researchers and research participants (Hume-Cook, et.al. 2010, p.166; Parr, 2007, p.129) Therefore, I expected a number of benefits from this approach. First, applying PAR enabled me, as a novice participatory action researcher, to gain direct experience in working *with* people, and not on or for them (Sayers, 2006). Second, it also enabled the research participants and me to directly practice the philosophy of valuing all people (Wolfensberger, 1992) throughout the research process. This was a chance to learn together and from each other, for PAR assumes that everybody knows something, rather than that experts are the only people with knowledge. Finally, PAR enabled me to directly practice this pearl of wisdom: 'from little things, big things grow.' I would like to be able to contribute to a welcoming society (a 'big thing') through this study (a 'little thing'). I consider this as such due to it representing a small and limited step with regard to disability awareness-raising. In contrast, many more disability awareness-raising initiatives are needed to create the ideal of a welcoming society for everyone, including PWD.

b. The Schedule

The next key step in this study was to establish a manageable timeline. PAR may involve a great deal of time investment due to the process of collaboration with research participants (Klocker, 2012). However, in all research there are always arising issues and events that can impact the research process. This requires flexibility on the part of the researcher and a clear and realistic schedule in designing a plan. The following schedule was set to manage the limited resources (time and funding) available for conducting this PhD PAR

From June 2010 to September 2010, I carried out the following activities: first, written and audio visual materials on disability awareness were reviewed; second, initial contact with participants to inform the research idea was made; and finally, a Critical Research Group (CRG) was formed, which included discussing and negotiating the detailed process of this research project with the participants, along with preparation for the fieldwork in Indonesia.

From October 2010 to June 2011, I carried out the following main activities: conducting interviews with the CRG; conducting group discussions with the CRG to develop the disability awareness-raising strategy; collaborating on producing a disability awareness video as a trial.

c. The first Individual interview

Initially, the recruitment process of the CRG members and the process of data collection with them (see Chapter Three on research methods' section) was planned to be conducted in three months, but the final timeframe was a five-month period from October 2010 to February 2011. The process was longer than the initial time estimated. This was due to the illness of the researcher and extreme weather in Jakarta, which caused bad flooding in the city and surrounding areas. Floods, and also other environmental disaster disrupted transportation, electricity and internet connections in several areas, causing communication difficulties for the researcher and members of the CRG.

Based on observations of the participants' recruitment process as described in the research method's section of Chapter Three, in this section I established brief profiles of the CRG participants, which confirmed that they correspond with the inclusion criteria. These profiles are presented in Table 4.1.

Table. 4.1 Brief description of the CRG participants

	Age	Sex	Disability	Education, Country & Scholarship	Location City of Resident
1	36	M	Low vision	Master degree - USA (Ford Foundation scholarship)	Jakarta
2	35	M	Physical	Master degree – the Netherlands (Ford Foundation scholarship)	Surabaya - East Java
3	48	F	Totally blind	PhD (Vreij Universiteit, Amsterdam, the Netherlands); Master degree - UK (British Chevening Award – British Council).	Jakarta (Amsterdam)
4	44	F	Physical	Master degree - Australia (Australian Development Scholarship)	Jakarta
5	34	M	Totally blind	Master degree - Australia (Australia Leadership Awards fellowship)	Jakarta
6	30	M	Totally blind	Master degree - UK (Ford Foundation scholarship) Master-Singapore	Singapore (Yogyakarta)
7	60	F	Physical	PhD - Australia (Australian International Development Agency Bureau)	Bandung - West Java
8	38	F	Physical	Master degree - USA (Ford Foundation scholarship)	Yogyakarta - Central Java
9	38	F	Physical	PhD - UK (World Bank, Japan-Indonesia Presidential Scholarship) Program; Master degree - UK (British Chevening Award – British Council).	The United Kingdom (Surabaya)
10	54	M	Physical	PhD and Master degree – USA (Fulbright)	Jakarta

Table 4.1 also shows that of the 10 participants, five participants lived in Jakarta, the capital of Indonesia; one participant lived in Bandung, the capital of West Java, one participant lived in Yogyakarta, a special province located next to Central Java; and one participant lived in Surabaya, the capital of East Java. Two participants lived abroad due to their postgraduate study, so we communicated via email and phone.

After establishing brief profiles of the CRG members, I contacted each of them via phone and email to discuss and negotiate the detailed process of the proposed research, and arranged an appropriate time for data collection with

each participant. Some challenges arose with regard to the first individual interview. National disasters in Indonesia (the volcanic explosion of Mt. Merapi in Yogyakarta, and Mt. Bromo near Surabaya) again caused technological difficulties in contacting several members of the CRG. Alongside this, the tight work schedule and the work commitments of each CRG member often made it difficult for participants to keep to the scheduled interview times.

Other challenges were related to the member-checking process. Initially, I thought that all the CRG members should be involved in member-checking the transcriptions of my interviews with them. I had thought this was needed to help comply with the principles of research rigour, and the ideal of 'full participation' within PAR. However, in the end, my transcriptions were provided only to the participants who wanted to read them. The CRG participants expressed the feeling that it would be a waste of time if every participant read each interviews' transcription. Moreover, there was the possibility that CRG participants would find it difficult to spare the time, due to their tight schedules. If there was anything that needed to be clarified, the researcher could ask the relevant participant before the upcoming interview or group discussion.

Reflection Box 4.3 The CRG advice = PAR principle

The CRG suggested that it would be better to ask every participant whether they were available to check the interview transcripts. I decided to follow their advice and request. I did this as my way to 'respect participants' – which is one of PAR's principles and as implementing the 'degree of participation' in a continuum, 'to acknowledge that various forms of participation may be valid at different times during a research process' (Kindon *et al.*, 2010, p. 16). This was also confirmed by the explanation from Denscombe (2010, p. 189) that checking the transcript with the informant should be done wherever possible.

Finally, the first individual interviews with all ten CRG participants were able to be conducted, and were held from November 1 to November 27, 2010 (see Chapter Three for the questions/content of the first individual interviews).

Based on the experiences and understanding resulting from the first round of individual interviews, an expectation to achieve a richer exploration and analysis of key issues related to the current level of disability awareness in Indonesia surfaced. From this, I decided to use videos for the second interview to elicit important discussion points, ideas and comments from the CRG members. They agreed with my idea and even suggested including documentary videos from the DSC-UI.

Accordingly, I randomly selected several videos from the DSC-UI, and also from the internet-based video database *YouTube*. As mentioned in the previous chapter, the DSC-UI and a local television station in Jakarta were planning to make a documentary video of 13 Indonesian people with disabilities. The project had been completed when I started the PAR stages of this study. Considering that there would not have been enough time to watch every single video available, the CRG suggested to watch at least three of the videos from the DSC-UI project which were randomly chosen, together with the videos from YouTube that I had watched and reviewed concurrently. The following is a brief description of those five videos:

- Video 1: *Semangat Tak Pernah Runtuh/ The Spirit Never Collapses*; duration 24 minutes. Presents stories about persons with physical disabilities caused by the Yogyakarta earthquake in 2006, who at the time were working for the Mandiri Craft Company creating and selling educational toys in Yogyakarta, as well as exporting them to foreign countries, such as Korea and Taiwan.
- Video 2: *Bisik cinta seorang ibu/ A Mother's Whisper of Love*; duration 24 minutes. Presents the life stories of two children with hearing impairment, namely Roza, a 5th grade primary school student in Sleman, Yogyakarta, and Vazza, a student at Gajah Mada University & University of Yogyakarta.
- Video 3: *Memandu langkah kecil/ Guiding Small Steps*; duration 24 minutes. Presents the story of Fitri, who had been visually impaired

since 5th grade in primary school. She graduated with a Master degree and founded a free school for street children in Solo, Central Java.

- Video 4: A Gift of Kindness; duration 01:06 minutes. A video from YouTube in the form of a TV commercial in Nepal, which depicts a woman using a wheelchair to carry out worship at a temple with a stairway.
- Video 5: Think! A Wheelchair User's Daily Struggle; duration 02:48 minutes. A video from YouTube in the form of a Public Service Announcements (PSA) in the USA, which shows the struggle of a woman who uses a wheelchair to do her shopping.

I provided the participants with these five videos, and asked them to watch them before the second individual interview to elicit their thoughts and ideas on the important points or noteworthy aspects with regard to the key issues of the disability awareness

d. The second individual interview

This interview involved nine CRG members and was conducted mostly in their offices and their homes as per their choice and availability, from January 5, 2011 to February 21, 2011 (see Chapter Three for the questions/content of the second individual interviews). These interviews tended to last longer than planned due to various reasons, including the enthusiasm to discuss issues related to disability awareness, a lack of clarity regarding the definition of a disability awareness video and the lack of availability for disability awareness audio-visual materials in Indonesian.

There was an incident where one of the CRG participants, who was living abroad for his studies, told me to let him use his right of participation as stated in the informed consent so that he could withdraw from the research without any penalty or obligation. This was due to communication and timing difficulties, caused by a hacked email account and a damaged mobile phone. After these issues were resolved, he discovered that he had lost all of his contacts and could not reach me. We eventually found out about his situation

when we finally called him—in the midst of meeting a deadline for his study. He proposed to quit temporarily and promised to get involved again at the next stage; thus, this participant was not involved in the first cycle of this PAR, but kept his promise to participate in the rest of the activities as soon as he had accomplished the formal requirements and obligations of his study.

d. Group discussion

This discussion was held on February 22, 2011 and involved four participants (CRG 3, CRG 5, CRG 7, and CRG 10). The other five participants (CRG 1, CRG 2, CRG 4, CRG 8, and CRG 9) were unable to attend due to changes to their work schedules. Furthermore, they were also living in remote areas, where communication via Skype was difficult due to the lack of internet connection (See Chapter Four for the content of the group discussion).

Another challenge was that not all interviews and discussions could be conducted in English, since the participants were graduates of foreign universities. After the first interview, some participants felt awkward talking in English since many of them rarely used English in daily life after they finished studying and returned to Indonesia. Therefore, they asked to use Indonesian in the discussions. I understood this request, and consequently, it resulted in the need for a longer timeline than estimated, because I had to transcribe interviews into Indonesian first before translating them into English. I could not finish the transcription of the group discussion by the end of the first fieldwork period, and continued it in Perth. This incident delayed commencement of the second fieldwork session in Indonesia, which was the next stage of this PAR.

The above description of the group discussion brings to an end the observation stage of cycle one. This stage provided a sound base for reflection which is presented in the Reflection Box 4.4.

Reflection Box 4.4 The Decision about the most appropriate disability awareness-raising strategy to be developed

Data collected during the observation stage, and especially the results of interview 1 and interview 2 align with the thoughts and ideas of the CRG about disability awareness-raising strategies. It highlighted that a disability awareness video is the most preferred and needed disability awareness-raising strategy to capture and communicate the reality of life for Indonesians PWD and the current situation of disability awareness. Accordingly, the study summarised the CRG's ideas into a table which would serve as the guidelines to create a positive disability awareness video for Indonesian people and the Indonesian context. Despite several limitations regarding the resources of the research and the challenges associated with making videos, we decided to implement the CRG guidelines to create a disability awareness video (DAV). Through this trial, we were able to gain knowledge that this DAV would be the most appropriate disability awareness-raising strategy.

The reflection confirmed the decision to create a disability awareness video and helped generate a sound base for the planning stage of cycle one

4.3.1 The planning stage of the video making cycle

This stage involved three activities: recruitment of video participants; recruitment of technical crew; and the technical preparations of the videomaking.

a. Video participants (VP)

Initially, I thought the CRG members could be the actors in this disability awareness video. However, this was not possible since the timing of the PAR stages in this study was not compatible with their tight schedules. Therefore, they suggested using the assistance of several other Indonesian people with disabilities as video participants or "talent" (a broadcasting term for actors) in the video. The CRG members believed that it was also good to allow more Indonesian people living with disabilities to share their knowledge, needs, interests and aspirations.

However, several of the people with disabilities, who were contacted by the CRG to be our participants for the videomaking, were not able to commit to our project due to incompatible schedules, and for some, their family members refused to let their disabilities be broadcast publicly. This limited the variety of participants available. Ultimately, the CRG and I secured the participation of three people who agreed with the proposed plan and scenario, and their significant others, such as their families or friends who accompanied them during the video-shooting time in the field and voluntarily participated in this study. The three main participants for the video were one male undergraduate student with a visual-disability; one female undergraduate student with a hearing-disability; and a male wheelchair user who had already completed his Bachelor/Undergraduate degree. All of them lived in Jakarta or the surrounding area.

Reflection Box 4.5 Recruitment of video participants reflected the existing disability model in Indonesia

The refusal to be an actor or video participant arose with families who did not want the disability of one of their family members to be known to the public. This was an understandable, overprotective reaction of the families who wanted to avoid the stigma of disability for their family and their concerned family members. The literature, especially that relating to medical models, has widely discussed such situations all over the world. Although such worry is understood, it limits the possibilities and opportunities of PWD to live like others who do not have disabilities. It has also been reported to contribute to the development of low self-esteem in PWD.

On the other hand, the willingness of some PWD to be actors/video participants revealed that they and their families thought that their disabilities were not something that should be hidden. By becoming an actor/video participant, they had the opportunity to express their thoughts and educate those who would watch the video. The phenomenon of refusal and willingness to become video participants reflected the reality of the influence of the medical model and the social model of disability issues in Indonesia.

b. The recruitment of technical crew

Initially, the second fieldwork was estimated to commence in April, however, due to delays, it had started in June. Consequently, a number of activities were also delayed. This caused some changes, such as a change in the technician team for the production of the video.

The original plan was that the CRG and I would be assisted by a local TV station crew, who had worked collaboratively with the Disability Study Center of the University of Indonesia since late 2008 and had produced 13 videos on Indonesian persons with disabilities. From August until September 2010, these documentary films aired on a programme for local TV in Jakarta, Indonesia. Through my involvement in that process, I had developed a close relationship with the programme crew, consisting of the producer, the script writer/reporter, and the cameraman/editor. In November 2010, when I was on my first field trip to Jakarta, I informed them of my research and that I was looking for full technical support from the local TV station to produce a disability awareness video. At that time, they agreed to assist me as my proposed timeline fit with their schedules and resources. I made my way to Indonesia in June, which was later than the originally proposed time of April 2011. I then discovered that the local TV crew was not available to assist me with the development of the video because of prior commitments.

Since it was not possible to work with the TV crew, the steps for completing the research process had to be amended. The actual process became more difficult and took longer than anticipated. This affected the proposed timelines for all subsequent stages of the second field trip. In order to find a replacement TV crew to assist with the development of the DA video, I consulted several members of the CRG for their advice. The CRG suggested that I contact some production teams that may be able to help me. Four CRG members from different parts of Indonesia provided me with the contacts of five production teams. The CRG from East Java provided the contact of one team based in East Java; the CRG from Yogyakarta provided one team based in Central Java; the CRG from West Java introduced one team based in West Java; and the CRG from Jakarta offered me two production teams based in Jakarta. I wished to work with the teams that were based in Jakarta, since geographical location can cause difficulties in coordinating and organising production due to cost, resources, and scheduling. However, both of the production teams in Jakarta were in the midst of other projects that needed their attention.

A month had elapsed, and the CRG and I had still not secured the services of a crew. This setback made me quite frustrated because of my very tight timeline and limited budget. The flow of research would need to be halted by a month until September 2011 to be in line with my scholarship requirements. I approached Professor Bambang S. Laksmono - the Dean of the Faculty of Social and Political Sciences, University of Indonesia - who gave me a letter of support to conduct my research prior to receiving the ethical approval from Curtin University. He helped me to recruit the assistance of students from a vocational program majoring in broadcasting. During the first meeting with these students, Professor Bambang and I briefed them on my intentions for the video and my research. Due to the fact that it was the semester break, some of the group members had prior engagements on traineeships with another broadcasting media, but they promised they would work productively on this video project. Finally, in late June 2011, I had a crew to assist me with the development of the video.

c. The technical activities for preparation of video making

This activity took two weeks and officially began the day after our first meeting, which was facilitated by the Dean. It commenced with brainstorming the technical aspects of the video making that covered ideas on period and budget, type, location, and the message.

- Period and budget

Discussions about the budget, time and schedule for producing the video were challenging, as will be described further in the following Reflection Box 4.6. Finally, it was agreed that we would try to develop a disability awareness video in a total of eight weeks, from June 27, 2011 until August 19, 2011. This consisted of two weeks for pre-production, two weeks for production, and four weeks for post-production. The crew estimated this timeline for production in consideration of the high cost of renting the video filming equipment. The cost of the video production was agreed upon and included the cost of renting equipment for two weeks; the crew's fee for eight weeks employment; some money for reimbursement of the participants' transportation and communication expenses; and their food and drink during the filming.

Reflection Box 4.6. Challenging preparation for video making

Changes, for example in terms of the increased number of technical crew required, has led to an unexpected consequence that arose during the course of this study. The consequence was mainly: the need to increase the budget to pay the technical crew and rent the video-filming equipments. This stage became critical since the technical team and I needed to adjust the production plan regarding the budget and the period of work. To be cost effective, the rental fee, the number of video participants, and the period of time for filming needed to be adjusted optimally. Based on the experience of the technical crew, with a total crew of seven broadcasting students, two weeks of shooting/filming was needed for five to six video participants.

- The type of video to be developed

As decided and mandated by the CRG members in the previous activities, we agreed that we would develop a non-fiction, semi documentary video to serve as a Public Service Announcement (PSA). In essence, this meant that the VPs in this video performed as themselves in their daily routines while articulating their lived experiences as Indonesians PWD. This video was also intended to function as an audio-visual instrument for a disability awareness campaign or training to educate viewers on issues pertaining to disability in Indonesian society.

- Location

Due to the limitations of budget and time, we decided that the location for the shooting/filming and production would be Jakarta and the surrounding areas.

- The message

As suggested by the CRG, we tried hard to discuss a range of messages that were consistent with the video's purpose and content as instructed by the CRG guidelines for the development of a disability awareness video. This was done, while also taking into account the availability of VPs and duration constraints as regards the video's purpose as to a semi-documentary and semi-Public Service Announcement.

4.4.1. The action stage of the video making cycle

It was estimated that this stage would be conducted in eight weeks, starting on June 27, 2011, and finishing on August 19, 2011. However, in reality it took ten weeks until August 29, 2011. This stage commenced after the research team and the technical crew had agreed on the period, budget, type, location, and the message of the video.

After the technical crew prepared the equipment and technical aspects of producing the video, we began the action of filming the video participants (VPs) in the shooting location. The script was discussed with the VPs before and during the shoot. I was present during the filming of the video and my consent was sought when changes were needed to be made. For example, as some of the VPs had different time schedules due to their prior engagements, provisions were made to film them separately. This was different than originally proposed by the CRG and me, as we hoped to have filming occur concurrently with their natural interaction.

Yet, in respect of the VPs' situations, we decided that it would be best for all of us if the shooting schedule be tailored to the VPs' schedules and the availability of the filming equipment and crew. Therefore, the filming schedule was revised, and followed the plan presented in Table 4.2.

Table 4.2 Shooting Schedule Arrangement (2 Weeks=10 days work)

Day	INTENTION OF SHOOTING: illustrate: to	Video Participant (VP)	Setting/ Location
1	A. What it is like living with physical disability	VP I: PWD who use a wheelchair	
	a. Daily life with family & their opinions about VP	VP I, spouse & child	Indoor: VP's home
	b. Interaction with neighbours & their opinions about VP		Outdoor: VP's neighbourhood
2	c. Activities of VP: touring with club of modified motorcycles for people with mobility impairments	VP I & friends	Outdoor: meeting point of VP I and his friends
	d. Interaction with friends & their opinions about VP		
	e. Activities of VP: attending meeting on campus	VP I	Outdoor: from home to campus
3	B. Profile & description of his disabilities		
	C. Opinions and aspirations related to rights and problems of accessibility for persons with mobility impairment		Outdoor & Indoor: Mosque, Library
4	A. What it is like living with visual disability	VP II: PWD with visual impairment	
	a. Daily life: using public facilities; interaction with surroundings		Outdoor: from home to campus
5	b. Activities of VP : Praying at the campus' mosque	VP II & friend	Outdoor & Indoor: Mosque
6	c. Activities of VP : group study in the library	VP II & friends	Indoor: campus library
	d. Interaction with friend and others		
	e. Friends' opinions about VP		
7	B. Profile & description of his disabilities	VP II	Indoor: campus Library
7	Opinions and aspirations related to rights and problems of accessibility for persons with visual impairment		
8	A. What it is like living with a hearing disability	VP III: PWD with hard hearing	
	a. Daily life: using public facilities / transportation		Outdoor: from home to campus
	b. Explanation of the family of VP III	Father of VP III	Outdoor: park
9	c. Activities of VP: attending course	VP III & classmates	classroom
	d. Communication and interaction with classmates		
10	e. Activities of VP: communication and interaction during break time in campus	VP III & friend	Campus canteen and café
	B. Profile & description of her disabilities		
	C. Opinions and aspirations related to rights and problems of accessibility for persons with hearing impairment		

The weather also contributed to the difficulties that we faced while shooting the video, as it was cloudy or raining on some days. These conditions limited the variations that could be made to the recorded images as to the original scenario.

After the video shoot was accomplished within 2 weeks, the technical crew worked to compile all the audiovisual data produced during the shoot/filming. The data format was transferred from the camera cassette to a digital file for editing, and finally, to a DVD user-friendly format. The editing covered the technical aspects of the video, such as its duration, the sound quality, and the subtitles so that the video would also be accessible for people with a hearing disability. This editing process was considered as the first edit. On August 19, 2011, the first edition of the DVD was ready, with a duration of 16 minutes and 18 seconds. The agreed upon work timeline with the student crew also formally ended on that date. However, due to the video still needing feedback from the CRG and other participants of this study, with amendments possibly being demanded, I negotiated with the student crew to prolong their editing work at no extra cost. The video still required further editing, so that the cycle of the research process could be repeated.

CYCLE TWO: Second video editing

As illustrated in Figure 4.1, this section presents a detailed description of the second cycle of this PAR study. Cycle two comprised a full implementation of the four PAR stages. However, this cycle was not actually repeated at the same stage of the video making process during the first cycle. This happened due to limitations at the essential stage of video making: filming the participants' activities, opinions and aspirations. The action stage of the second cycle mainly repeated the video editing. Therefore cycle two is named 'second video edit cycle'.

4.2.2 The observation stage of second video editing cycle

The video that was successfully produced in the first cycle could actually be accessed by anyone without any special technical expertise. This would only

need the ability to operate a DVD player or computer equipped with a multimedia player facility. However, the transfer and editing process did not involve CRG participants due to time constraints and a lack of resources. Therefore, the first edition of the DVD -which was the outcome of the action stage of cycle one: video creation- still required the opinions or feedback from members of the CRG as co-researchers of this study. Consequently, I needed to send the first edition DVD to all ten members of the CRG to seek their feedbacks and opinions.

Reflection Box 4.7 Reasons for repeating cycles of the PAR process

Though we tried to make the video based on the guidelines as formulated by the CRG, especially for PWD in Indonesia, there was still the possibility that there would be a scene which was somewhat different from the thoughts and ideas of the CRG participants as stated in guidelines on making disability awareness video. Therefore, CRG participants, as co-researchers and as the experts in this PAR study were required to and provided their expert opinions and feedback on the video being developed. It meant that we needed to repeat the cycle of research process amid the limitations and constraints this study faced, including the following facts:

- Ramadan month which starts from the first of August 2011. In this month, every day Muslims should perform mandatory fasting, with extra religious worship such as *Taraweh* (congregational prayers) in every evening and they are expected to keep their normal activities during the fast. However, with the unusual sleeping and eating schedules, it was common that overall pace of life slows down, working hours became noticeably shorter, productive time seemed more limited. Therefore, to some extent it would be challenging to schedule tasks or events during Ramadan. In this study, Ramadan affected my opportunity to consult with the CRG due to both some of the CRG members and I also practice the Ramadan rituals. Therefore, they advised me to set a simple and doable planning related to the research activities so that our PAR process could be completed before *Idul Fitri*. In Indonesia, *Idul Fitri* is commonly called *Lebaran*, a festivity after completing the fasting of Ramadan month. Actually, *Idul Fitri* is a Muslim holiday celebrated for two days, which in year 2011 was 30 – 31 August. The Indonesian Government sets *Idul Fitri* as a national public holiday with official holiday period from August, 26 to September, 5. It is common that people took leave before the official date.
- The end of Ramadan and the *Idul Fitri* coincided with the ending of my second fieldwork. Therefore, the research activities should be done in ways so that it could be completed by the end of fieldwork period. Therefore, it was not avoidable that the editing video occurred in Ramadan month.

4.3.2 The planning stage of second video editing cycle

Since this second cycle occurred during the month of Ramadan, and since most of the technical crew, the CRG participants and myself were Muslim, we needed to engage in various mandatory and special religious activities during the holy month. Therefore, the next action required precise planning due to time constraints and limited opportunities.

Furthermore, due to the financial restrictions in the study, it was no longer possible to rent equipment needed for filming. Therefore, the response to feedback required the creativity of the research team to edit the first edition of the video from the data that we had from previous shoots, since we were not able to conduct any new shoots for new scenes or pictures.

4.4.2 The action stage of second video editing cycle

The core activity of this stage was to edit the first edition video, which was the outcome of the first cycle, based on the input from the CRG members. I sent the first edition DVD to all ten members of the CRG to seek their feedback, opinions, and approval. The CRG members were grateful that the video could finally be realised despite various limitations and challenges, such as budget, time, weather and the availability of the VPs. As reflected in their name 'critical research group', they provided critical feedback with great enthusiasm. Their feedback covered five issues. The details of CRG input will be stated in the next Chapter: research findings. For some of their feedback, the best response would have been to reshoot the footage. However, considering the limitations of time and equipment, they still agreed to approve the video as a disability awareness audio-visual instrument if some amendments were made based on their suggestions. Based on their feedback, the video was edited again and became the second edition with a duration of 12 minutes and 43 seconds.

CYCLE THREE: Third video editing

As illustrated in Figure 4.1, this section presents a detailed description of the third cycle of this PAR study. The cycle comprised a full implementation of four PAR stages and actually repeated similar stages of the second cycle. The

different was at the observation stage, which had different sources for participants' opinions and aspirations. The action stage of this cycle mainly involved a repetition of the video editing. Therefore this cycle is named the 'third video editing cycle'.

4.2.3 The observation stage of the third video editing cycle

In the cycle two, the video was successfully edited. Furthermore, the second edition of the DVD incorporated the opinions of Indonesian beyond those of the CRG. In order to reach many participants within a short time, the CRG participants and I concluded that a video session was held to receive a range of feedback from Indonesian persons with disability within a short time. This was important in terms of efficiency and effectiveness. Consequently, the CRG participants and I designed two video sessions for two different groups of participants: DPO members and undergraduate students.

To facilitate the participation of all prospective participants in the sessions, the CRG and I decided to:

- Indicate a venue that was reachable by all parties.
- Provide a boxed lunch to be brought home for all participants.
- Provide some money for reimbursement of transportation for the DPO participants.
- Express thanks by giving all undergraduate students and DPO participants a souvenir (a koala key ring from Perth).

Before the session, based on the CRG's suggestions, I drafted a simple form to elicit feedback from participants. The draft was then given to the participants, although due to the previously mentioned scheduling complications related to Ramadan, it was not thoroughly examined by all CRG members. Moreover, the scheduling difficulties also prevented me from conducting a trial or testing the statements on the form before using it in the session. The CRG members said they trusted me to use the form that I had drafted, and that the most important thing was to receive feedback from the participants. If the possibility arose, the CRG suggested enhancing the feedback by carrying out voluntary

loosely-structured interviews or discussions with some participants from each session to enrich the information on the feedback forms.

Three sessions were conducted as follows:

- a. A session with DPO members was held on August 23, 2011 at the Indonesian Non-Government Organisation for Indonesian paraplegics in Jakarta. There were 30 disabled participants, consisting of people who were blind (visually impaired), deaf (auditory-verbally impaired) and physically disabled (mobility impaired), especially wheelchair users.
- b. A session with 20 students from various undergraduate programmes was held on August 24, 2011 at one of the state universities in Jakarta.
- c. A session was held on August 25, 2011 with 30 students from various undergraduate programmes at one of the private universities in Jakarta.

The sessions were operated as follows:

1. Ice breaking

- Greeting and thanking the participants, getting to know each other based on the attendance list.

2. Introduction

- I explained that the session was related to my study.
- I distributed the participant information sheet to be read and gave them the opportunity to ask questions they wanted to be clarified. Afterwards, I handed out an informed consent sheet to be signed.
- I explained that I needed to know their opinion regarding the issues of people with disabilities in Indonesia, so I had prepared a feedback form to be filled out after the video show. I preferred not to name it an 'evaluation,' since the word could imply connotations of a test. I emphasised that it was not a test because there were no right or wrong answers, but that I needed their honest opinions. I ensured their confidentiality, and they had no need to put their names on the sheets.

3. Video show

- I played the video for the participants. During the session with DPO members, in order to be more efficient and effective due to time and

space constraints, participants with visual impairments were paired with participants who were wheelchair users so they could help state everything that was depicted in the video.

- After the video show finished, I distributed the feedback form to be filled out as to their opinions on the video.

4. Discussion

- After they completed the feedback forms and thanked me for allowing them to participate, I asked if any of them were interested in further discussing their feedback.
- Three people from the DPO and two students from each university agreed to participate. The discussion was loosely structured around a checklist of discussion points covering their general comments/opinions about the feedback form and the video.

Reflection Box 4.8 Juggling roles

Delays and changes to the commencement of the second fieldwork required some adjustments to the implementation time of the research schedule. The CRG advised that the video sessions should be conducted at the same time as the video editing, so that the results of the discussion would be incorporated into the video being developed. Therefore, a complete video would be finished by the end of the fieldwork period in Indonesia.

Although the advice from the CRG was essential and very rational, the implementation was much more challenging than I had envisioned. In less than two months we had to prepare and conduct the video sessions, and then reflect on the feedback from the sessions to the editing of the video. Juggling the demands and priorities of being the participatory action researcher, organiser, as well as the producer of the video with limited time and financial resources was full of struggle.

4.3.3. The planning stage of the third video editing cycle

This stage was similar to the planning stage of cycle two with regard to time constraints, limited opportunities, and financial restrictions for additional

filming. Therefore, the response to the feedback from the observing stage in this cycle also required the creativity of the research team to edit the second edition of the video from the raw data that we had from the initial shoot, and other possible resources available, since we were not able to conduct a new shoot for new scenes or pictures.

4.4.3. The action stage of the third video editing cycle

The second edition video was trialled and showcased from 23-25 August, 2011, to DPO members and undergraduates participants, from whom feedback was obtained. Based on their feedback, the video was revised to be the third edition with a duration of 13 minutes. This third edition video was given to me on August 29, 2011, the last day of the video production stage. It took a total of ten weeks, which was longer than the estimated eight weeks. This video was considered to be the final video in Indonesian language. It had not been embedded with English subtitles due to time limitations, since it was only one day before the public holiday Idul Fitri, celebrated for two days on August 30-31, during which most official businesses were closed. It is also common for people to travel to their hometowns or other cities to celebrate the holiday with their families and relatives during this period. This was the case for my student crew, who were mostly Muslim. Moreover, they had given an additional two weeks of extra editing at no extra cost since August 19, 2011, which was the original due date of the video development. Due to a lack of video editing skills and budget, the video was embedded with English subtitles in Perth in 2012, when I finally got the assistance of an undergraduate student who majored in media. The editing process was often challenging because I needed to constantly remind the broadcasting student crew that the video is an important part of this PAR PhD study that aimed at addressing the needs and interests of Indonesian PWDs. I had to emphasise that while it is good to include aesthetic or cinematographic aspects into the video, we had to prioritise the aims of this study and our respect for the Indonesian PWD who were participating in this study.

In summary, the research process in this study follows the PAR stages and a working PAR model as formulated by Suzi Quixley (2008, p. 10). This chapter

demonstrated how the four PAR stages of observing, reflecting, planning and acting have been repeated three times as part of PAR's cyclical process. Accordingly, the research process in this chapter was organised under three headings: cycle one-the video making, cycle two-second video editing, and cycle three-third video editing, with subheadings related to PAR's four stages in each cycle.

CHAPTER FIVE

RESEARCH FINDINGS

This study has three objectives. The first was to describe and analyze the realities of PWD's life in Indonesia. The second was to explore and analyze key issues on the current level and state of disability awareness in Indonesia. The final objective was to develop one of the disability awareness raising strategies proposed by the research participants of this study.

The research objectives were achieved through in-depth interviews and group discussions with the research participants. As this study used the participatory action research (PAR) approach, the in-depth interviews and group discussions were part of the data collection, which thus can be categorised as the 'observation stage'. Furthermore, PAR requires an 'action stage' (a product). Based on a series of in-depth interviews and group discussions, the participants (especially the Critical Research Group/CRG) proposed and emphasised that a disability awareness video is a crucial awareness-raising strategy which needs to be developed in Indonesia. Therefore, to achieve the third research objective, this study did not only focus on data collection, but also on implementing an action, namely, a video. Thus, the findings have been obtained through data collection and video-making (an action of PAR). The description of the video-making process demonstrates that a complete cycle of PAR (from observation to action) has been conducted. The aim of this was to offer a clearer and more comprehensive disability awareness-raising strategy in Indonesia as proposed and emphasised by the participants of this study.

This chapter presents the research findings of this study, based on each research objective, to demonstrate that all three objectives have been achieved. This chapter is organised into these three objectives as heading.

OBJECTIVE 1 - The Realities of PWD life in Indonesia

The discussion of the research findings related to objective one consists of two sections: first, a presentation of the profiles and life experiences of the CRG participants (the descriptions of the inclusion criteria and recruitment process of the CRG are described in Chapter Four). Second, a description of their views related to the realities of PWD life in Indonesia is presented. This involves a description of the realities of Indonesian PWD lives and covers three key issues: the first issue relates to broadly-known myths about disabilities as identified by the CRG members; the second relates to inappropriate social attitudes and behaviours influenced by these myths; and the third relates to insensitive government policies on disability issues

5.1.1 The CRG participants' profiles

A discussion of the CRG members' profiles in this chapter further expands the presentation of their brief profiles in Chapter Three. Further details about the members were acquired from initial individual interviews and further information was gathered during the research process. This is an important aspect to this study because the CRG were both advisors and active participants in this PAR. The similarities and diversities of the CRG members are also important to present

Their profiles in this section are presented using numbers instead of pseudonyms to replace their original name. The numbers indicate the order of the first individual interviews, which were based on their availability. Thus, CRG numbers do not indicate specific preferences or reasons. The numbers will be used as references to their identity when excerpts of their statements are used in this chapter.

1. CRG 1 was a 36-year-old man, who was born with low vision caused by Glaucoma. His schooling took place in an 'ordinary or mainstream' school as

there was no special school in his home town, the Riau Islands, Sumatera. In 2009, he graduated with a Master's degree in rehabilitation and clinical mental health counselling from the United States. He lived and worked in Jakarta. He was active in one of the Blind Foundations in Jakarta and worked as an inclusive education consultant at one of the international foundations concerned with blindness - in its branch office in Jakarta. He was also active as a seminar presenter and trainer, both within Indonesia and internationally. His job and activities made him a frequent flyer where he travelled to three different parts of Indonesia or abroad on a weekly basis.

2. **CRG 2** was a 35-year-old man. His left foot was physically impaired due to cerebral palsy that developed when he was seventeen months old. He used crutches and a scooter for people with mobility impairments, which he received while studying for his Master's degree in the Netherlands. He graduated with a Master of Humanitarian Assistance in 2005. He had been active in several Disabled People Organisations (DPOs) since 1996. He initiated the Association for the Disabled in his home town and established the Centre on Community Development and Empowerment for People with Disabilities in Surabaya-East Java in 2006. He was an active speaker in seminars and workshops about disability and a facilitator of training programmes for PWD. He lived and worked in Surabaya at an advocacy NGO for people with disabilities.

3. **CRG 3** was a 48-year-old woman. The virus *Retinitis Pigmentosa* affected her at the age of 10, which resulted in poor vision. She became totally blind when she was 17 years old. She graduated her Master of Public Administration from the University of Indonesia in 1997 and a Master of International Communication from the United Kingdom, in 2006. She was actively involved in several DPOs in Jakarta. In 1992, she founded the Special Bureau for the blind in the Jakarta Catholic Archdiocese. She lived and worked in Jakarta at her institute, established in 2009, with the mission of mainstreaming disabilities for a better life. This institute was established by her after she resigned from an international foundation for blindness in Indonesia. In September 2010 she started her PhD programme at Vrije Universiteit, Amsterdam, which focuses on people with leprosy in Indonesia.

4. **CRG 4** was a 44 year old woman who has been physically disabled since she was 14 years old due to an unknown disease at the time. She used crutches to walk short distances and a wheelchair for long distances that are over 100 meters. In 2000, she completed her Master's degree in disability studies in Melbourne, Australia. She participated actively in several DPOs in Jakarta. She was active as a presenter in national and international conferences, workshops, and training programmes related to disability issues. She also actively published on disability issues in several Indonesian magazines and newspapers. She lived in Jakarta and worked as a government officer.

5. **CRG 5**, a 34 year old man, was totally blind by the age of 23. At the age of eight in 1984, he was exposed to the virus *Retinitis Pigmentosa*, which resulted in poor vision. He was active in several DPOs in Jakarta. He worked as a trainer and an advocacy officer in one of the international foundations engaged in disability issues at its Indonesian branch office. He lived in Jakarta and worked as a trainer for the Disability Studies Centre of the University of Indonesia. He then obtained a scholarship to attend international training for disabilities issues in Tokyo, Japan, and Australia, before continue studying Master's degree in Social Work and Disability in Adelaide, Australia in 2012.

6. **CRG 6** was a 30 years old man who had been totally blind since age 11. This was due to a genetic disorder in his eye nerves which resulted in low-level vision from the age of two. He had dedicated his career to advocating for the rights of people with disabilities in Indonesia and founded in 2003 a DPO called 'Integration and Advocating Forum for the Disabled'. His main activities in the organisation include capacity building and organization at a grassroots level through various forms of training, publications, and campaigns. He has also been one of the lead researchers at the Centre for Disability Studies and Services at the Islamic State University in Yogyakarta, Indonesia, since 2010. At the national level, he initiated the Anti-Discrimination National Front. He obtained his Master's degree in Disability Studies from the University of Leeds, in the United Kingdom, in 2008. He obtained a scholarship for his Master's in

Public Administration at the Lee Kuan Yew School of Public Policy, National University of Singapore, in 2010 and graduated in 2011.

7. **CRG 7** was a 60 year old woman. Her left foot was physically impaired due to contracting the Polio Myelitis virus when she was eight years old. She earned her PhD from the University of New South Wales, School of Town Planning, Sydney, Australia, in 1996. She lived and worked in Bandung as a researcher at the Centre for Research and Development on Settlement, Ministry of Public Works. She was active in the DPOs based in Bandung. She has actively published her writings on disability issues with a focus on the development of barrier-free environment in several journals in Indonesia and abroad, and also in Indonesian newspapers.

8. **CRG 8** was a 38 year old woman who had polio at the age of four and half. Since then, she has had to use crutches or a wheelchair. She was active in international fora and training programmes on disabilities. In 2008, she graduated with a Master of International Health Policy and Management from a university in the US. She has published a book, *Meretas Siklus Kecacatan: Realitas yang Terabaikan (Breaking through Disability: The Forgotten Reality)*. Since 2009, she lived and worked in Yogyakarta as a programme manager of an NGO for wheelchair users in Indonesia.

9. **CRG 9** was a 38 year old woman who uses a wheelchair due to a spinal cord injury she endured when she was 21 years old. She graduated her Master of Accounting from a public university in Surabaya, Indonesia, in 2006, and also earned a Master in Disability and Social Policy from the University of Leeds in the United Kingdom, in 2008. In 2006, she founded and became the director of an NGO formed to empower people with disabilities, which based in Surabaya. Since 2008, she has been a lecturer in accounting at a private university in Surabaya. She obtained a scholarship to pursue her PhD at the University of Hull, United Kingdom in 2010.

10. **CRG 10** was a 54 year old man who used a wheelchair due to a spinal cord injury he sustained in 2003 at the age of 46. Ten years before acquiring

his disability, he earned his Master's and PhD degrees in Child and Family Development and then a postdoctoral fellow in the US supported by a Fulbright scholarship. He was a prominent Indonesian figure on child protection and children's rights issues, and an activist on AIDS prevention and drug abuse problems. Various accolades and awards from Indonesia and elsewhere have been conferred on him. After he acquired the disability and used a wheelchair, he admitted that he experienced many challenges to participating in normal daily activities, but he continued to be strongly committed to supporting marginalised groups, such as people with AIDS, drug abusers, vulnerable children, and PWD. His academic career culminated with his appointment as a professor at a university in Jakarta in 2008. This achievement made him the first Indonesian wheelchair user to reach this highest academic level.

In addition to the CRG profiles presented above, all of these individuals have visible physical disabilities that are mobility related. Six of the 10 participants, use mobility aids such as crutches, wheelchairs, and scooters. Four participants have visual impairments and used white canes as their mobility aids. Six participants (CRG 1, 2, 4, 7, 8 and 10) were employed full-time, one person (CRG 5) was employed part-time, one person (CRG 3) was self-employed, and two people (CRG 6 and 9) were undertaking postgraduate study in an international setting, and thus were not currently employed.

The CRG profiles reveal that the majority have lived with disabilities most of their lives. Out of the 10 participants, one person (CRG 1) had been impaired since birth (congenital disability), and nine CRG members had acquired a disability later in their lifetime. Out of the nine members, six people (CRG 2, 3, 5, 6, 7 and CRG 8) became impaired during their childhood due to disease or illness; one person (CRG 4) acquired a disability in her adolescence due to disease, and two people (CRG 9 and 10) became disabled in their adulthood due to injuries.

The CRG profiles also revealed differences as to the cause and age of the onset of their disabilities. However, each of them had experienced hard challenges and an arduous journey. It appeared that their current

achievements were attained through extraordinary struggle accompanied by acceptance and large amounts of support from their families and significant others. However, there were other people who were unwelcoming to them. This was indicated in excerpts from their life stories such as the following:

My life completely changed after I contracted polio at the age of four and six months. I didn't understand why I had lost all of my strength and could not move my body. I was unable to walk and had to be carried everywhere. I was lucky to have a daily caretaker who was the most patient, loving and caring person I had ever met. I was extremely fortunate that my father and my mother always wanted me to get an education. My father supported my education by providing the books and English tutor that I needed. After high school I went to university, received a law degree. In August 2005, I was awarded a scholarship from the Ford Foundation. I was one of the 46 fellows that had been selected from 3,000 applicants throughout Indonesia. I left in June 2006 and in 2008 I earned my Master's degree from the United States (CRG 8)

Another illustration of a CRG's lived experience showed that:

We were capable of studying and graduating with higher degrees from overseas universities with international scholarships which we earned through fair competition. International scholarship institutions and universities hold positive awareness and believed that people with special needs or disabilities should be granted the same rights. In 2009, I graduated with a Master's degree in the United States (CRG 1).

These excerpts illustrate that acceptance, social support, and positive awareness were very important for them to successfully obtain their postgraduate degrees from international tertiary education institutions. Thus, they are also evidence of their great abilities and capabilities.

5.1.2. The CRG participants' lived experiences

In this section, the CRGs' stories illustrate the challenges, barriers and achievements that are part of their lived experiences. These include several key issues, including the difficulties associated with being accepted, the importance of having meaningful interpersonal relationships with others, and ensuring their mobility and access to education and employment.

5.1.2.1. Difficulties in being accepted, and included in their communities

Most of the CRGs' lived experiences reveal that they were often regarded by the Indonesian public as weird, not normal, unfavourable, and undesirable due to their impairment. This was revealed in the following life story:

I contracted polio at the age of four years and six months. I was unable to walk and had to be carried everywhere. My father didn't like to see my caretaker carry me in public so I never left the house except to go to school. ... When I was 10 years old, I started walking with two crutches and brace on my left leg which was not easy. People stared at me everywhere I went with two crutches and a brace on my left leg. Their stare made me feel that there was something wrong with me. I was struggling to accept myself for who I was. I felt excluded, not welcomed.
(CRG 8)

Another CRG participant explained: "due to our physical appearance, we are often interpreted as being 'others', as different in a negative connotation [sic]. We are not aliens; we are part of the society" (CRG 2)

5.1.2.2. Difficulties in having meaningful interpersonal relationships with others

According to most of the CRG participants, it was very difficult to have a meaningful intimate relationship. Indonesian people are not in favour of giving, or found it difficult to give consent if their family member was to have a relationship with a person with a disability especially when they were looking to be partners or a couple. This was evident in the following life story:

I struggled to be accepted by my father-in-law and to get permission to marry his daughter. I was confronted by the image that as a person with

disability, I ought to feel inferior due to the impairment on my left foot. It somehow defined that my whole body and personality were also being impaired [sic]. It seemed that he perceived that my impairments were equated with lower social roles, an incapability to have a happy marriage, an incapability to make a living to support a family. The worst assumption was that my impairment would be inherited to their offspring due to the myth that disability is a contagious disease. These negative perceptions continued, although I had graduated with a Master's degree overseas and had a stable job. Fortunately, this negative belief was removed when I was blessed with a healthy daughter without any impairment as feared by the members of my wife's family (CRG 2).

Interestingly, despite these barriers to having a relationship with a person with a disability, seven of the 10 CRG members were married and three of them were in an intimate relationship.

5.1.2.3. Difficulties in gaining access for mobility

Access for mobility was identified as one of the key difficulties experienced by most CRG participants which often motivates them to do something better such as achievement and advocacy. This was illustrated by a story of CRG 8:

I needed a wheelchair because walking [with crutches and a brace] had become too difficult. Unfortunately, I didn't have access to a wheelchair and couldn't afford to buy one... in 2008 I earned my Master's degree in the United States. My studies broadened my knowledge, skill and ability to implement programmes focused on disability issues. When I returned to Indonesia, I applied that knowledge to create 'post disability programmes'. I wanted to create these programs because I had experienced first-hand how difficult it is to get mobility access and opportunities for a better life in Indonesia. (CRG 8)

Another mobility problem related to the design of cities, which does not take into account people with visible impairments/disabilities, as indicated in the following comment:

I face so many mobility challenges to participating in normal daily activities in Jakarta as all public facilities are inaccessible. The city design is made in such a way [sic.]¹. I am very lucky because I have money to afford a car, driver and an assistant. Otherwise I would have to live by myself in my wheelchair, and it would not be possible for me to live in Jakarta (CRG 10).

Another mobility problem experienced by a participant was expressed as follows:

I found it difficult to get access to buildings in a mainstream school. I walked with crutches and a brace, which was not easy, as the school was a multi-storey building. Only stairs, no ramps. I had to put in great effort to move from one place to another. I had to overcome an inaccessible, 'unfriendly' school building, while other students without disabilities could easily use the stairs to get to class (CRG 4).

5.1.2.4. Difficulties in getting opportunities and access to education

CRG 3, who had a visual impairment, illustrated her lived experience associated with difficulties in getting opportunities and access to education:

I was prevented from joining a mainstream school because I could not see and read like other 'normal' pupils....Therefore I left Jakarta and went to a special school for students with disabilities in Malang. But I continued my education in another city namely Yogyakarta, not at a special school. Finally, I finished my undergraduate and Master's degree in Jakarta. After I received a scholarship from the British Council, I graduated with a Master's in International Communication in the United Kingdom, in 2006.

It is apparent that this participant was able to study in a mainstream school and even complete a higher education degree overseas. This contradicts the

¹ Throughout the chapter, [sic.] is used when I put quotations exactly as they spoke or wrote, even if there is something unclear or if the sentence may not be perfect due to some grammatical mistakes.

public ideas where it was suggested several times she move to other schools or cities where 'special segregated schools' were available. Due to her disability, she had to encounter such negative practices and policy rooted in the damaging perception that PWD not being fit and able for participation in regular schools.

5.1.2.5. Difficulties in employment opportunities and access,

The following story was retrieved from an online newspaper when I was informed by another CRG to look for the life story of CRG 9. This story describes her considerable difficulties in obtaining access to employment, for at the beginning of her story we also have a picture of her struggle to get access to education. Her story demonstrates continuous challenges and an arduous journey. She confirmed this with a newspaper article about her experiences, and gave me approval to use it as data for this research project. Part of the article is reproduced below:

She has experienced different and unfair treatment since using a wheelchair due to a spinal cord injury when she fell from a cliff during an activity with the Nature lovers' club of her campus in 1993. She used to study at the Faculty of Pharmacy in a public university in Surabaya-Indonesia, but the lecturers of this faculty pushed her to withdraw, although her friends supported her to continue. Finally, in 1994, she decided to move to the Faculty of Accounting of the same university, and started from the beginning again and finished her studies in 1998. She worked as a data management officer in the medical faculty in the same university from 1999 to 2003. In 2002, she took up a Master's degree in accounting and completed her study in 2005. Before graduating, she had applied six times for an academic lecturer position at the Faculty of Economics in her university but always failed. Later, she was told by the faculty leader that her failure was not because of academic inability, but because she is a wheelchair-user. In late 2004, she tried to register as a candidate for a civil servant officer-CPNS recruitment in the city government of Surabaya. Again, she was rejected because she was considered non-eligible. Using a wheelchair was interpreted by the city

council as not fulfilling the requirement of being ‘physically and mentally healthy’. She protested to the Surabaya city council, filed a lawsuit through the state administrative court in February 2005 and won—but her case took four years until the Supreme Court issued a decision in December 2009. It coincided with her 37th birthday so it exceeded the age limit to join the 2010 CPNS recruitment; however, her victory became the jurisprudence of cases of discrimination against Indonesian people with disabilities. Meanwhile, in 2006, she founded an NGO to empower and fight for discrimination against people with disabilities. In 2008, she obtained a scholarship and graduated with a Masters of Disability and Social Policy in the United Kingdom. In 2010, she obtained a scholarship to pursue her PhD at another university in the United Kingdom (Susilo, 2010).

This section highlights the various and numerous challenges that confront CRG members. The emphasis on physical barriers to access reflects their experiences of having physical disabilities. One aspect that is apparent is that whilst they have overcome considerable barriers to achieve their educational achievements and employment, they are still confronting barriers in their everyday lives in Indonesia.

5.1.3 The reality of Indonesian PWD life

The reality of PWD life in Indonesia discussed into three parts: The first section discusses findings related to the broadly-known myths about disabilities as identified by CRG members; the second outlines specific life experiences related to inappropriate social attitudes and behaviours influenced by those myths; and the third describes insensitive government policies on disability.

5.1.3.1 Myths about disabilities

Based on interviews and discussion with the CRG participants, it was revealed that the common dominant myths about disabilities that have remained intact in Indonesian society, include:

- (i) Disability is God's punishment; ancestor sins and represents disgrace
- (ii) Disability is a personal tragedy and misfortune
- (iii) Disability is a disease or sickness
- (iv) Disability means dependency

(i) Disability is God's punishment; ancestor sins and represents disgrace

The participants' identification of this myth could be understood from one of them who explained that "[there are] a lot of myths, assumptions about people with disabilities. Some people believe that disability is punishment from the almighty God so many people do not even get to interact with them appropriately" (CRG 10).

As expressed above, participants used words like 'assumption' and 'belief' to talk about myths and defined myths as assumptions and beliefs regarding disability and people with disabilities. The statement also revealed a link between this myth and inappropriate behaviour toward people with disabilities, such as keeping a distance from them or avoiding them.

Other reactions to this myth included: "I am annoyed about the myth, which often relates disability to my ancestor's sins (CRG 3) and "considers disability as a disgrace" (CRG 5). It is clear that according to both participants, when the public perceives disabilities as God's punishment, they perceive people with disabilities as an indicator of the sins or disgraceful background of persons and families with disabilities. In other words, this myth leads to an attitude of blaming the person or their forebears for what they must have done in their past.

Regarding this, the participants argued adamantly that disabilities are not God's punishment, nor are they related to ancestral sins and disgraceful acts of the past. Furthermore, all the CRG participants were grateful that this kind of thinking has not led to rejection within their families; however, they acknowledged that this myth has sometimes led to an inappropriate perception that persons with disabilities and their families "ought" to feel ashamed or sinful. This attitude may lead to people refusing to interact with PWD and/or to

see them having activities in the public area. The latter is also known as segregation, where it is assumed that people with disabilities should belong to a specific institution or area, and not be out in public.

(ii) Disability is a personal tragedy and misfortune

This myth was revealed in a participant's statement: "They perceive disability as a personal tragedy, while it should be (considered) as a social problem... this myth is unacceptable because disability is not a misfortune, nor is it a personal tragedy. It can happen to anyone, at anytime, and anywhere". (CRG 2)

From this statement, it can be seen that the participant rejected the myth that disability is a personal tragedy, a widely false belief that disability is the individual problem of a person who is perceived as a tragic victim.

Furthermore, another informant revealed that, "some people also believe that a person with a disability is not a complete person, and therefore they might interact with the person feeling much sympathy and pity. That is also not appropriate" (CRG 10).

According to the CRG participant, this myth has led to a negative attitude that perceives a person with a disability as a random victim of misfortune causing them to not be intact, so that other people should view and treat them with sorrow and patronising pity.

(iii) Disability is a disease or sickness

This myth was commented by participant: "there are people who think that disability is contagious, so people with disabilities must be excluded" (CRG 5). To give an example, this participant explained further that this myth has perpetuated the public belief that people would become visually impaired simply by being close to or interacting with people with visual impairment, or inheriting this from their parents. He and most participants further expressed the opinion that 'it is regrettable that in this day and age, this myth still persists,

while disability, in fact, is not a contagious disease, and people with disability never infect other people with their impairment' (CRG 5).

It can be seen that this myth has resulted in a negative attitude in the form of fear of being infected with or inheriting the condition, and this is manifested by the negative behaviour of social exclusion or rejection.

(iv) Disability means dependency

Disability is often assumed to mean that the person is dependent on others, and is indicated by the following participant's statement: "... I already get bored and annoyed by the belief that disability means dependency, thus people with disabilities 'should be' accompanied, and are not allowed to go alone [in public] so that they do not bother others [people without disabilities]. I am imposed as incapable of being independent by public attitude, public treatment, and public services [sic] (CRG 7).

Based on the above expression, it is clear that the participants feel misunderstood and imposed upon by this myth, which results in negative attitudes in the form of pity and seeing PWD as incapable of being independent. This myth leads to negative behaviours such as considering them unable to travel alone and underestimating their potential. Such 'low expectation' have had to be confronted by CRG members who then went on to defy such expectations.

The CRG participants argued that these four dominant myths still exist today because "they had been socially internalised from generation to generation and affected many people's individual views, without realising it. Means, these myths had been internalized unconsciously (CRG 5). As a consequence, people have taken these myths for granted as reality. This was exacerbated by situations such as the following:

Media such as television, movies, as well as books, often deliver wrong messages about disability that exploit the conditions of people with disabilities, or otherwise describes disproportionally their superhuman

capabilities. This happens because they don't consult with people with disability or DPOs; and are not aware of the stigma resulted by these damaging myths"(CRG 5).

Another participant argued that it happens because "the majority of Indonesians with disabilities do not have the channel to voice their life experiences and views in order to provide actual evidence about what disability means and what it's like to live with a disability" (CRG 3).

These damaging myths were identified by a majority of the CRG participants. These myths have influenced attitudes and behaviours toward disability and PWD in Indonesia, and they have made PWD lives more difficult than the actual impairments or medical problems themselves.

Although most CRG participants now live in big cities in Indonesia and have good levels of employment, most of them were born and have lived in small towns or rural parts of Indonesia. They have all experienced difficulties for example in accessing transportation, education, and employment. Although they now have better education and employment, and live in big cities, they still face many challenges due to the inaccessible environment. They believe that a worse reality is still currently being faced by other Indonesians with disabilities living in towns and rural locations in Indonesia. Also, some Indonesians with disabilities who have limited support and resources may be regarded as having high support needs—for example, those who have acquired brain injuries, people with severe cerebral palsy, people with chronic illness. These people will be easily isolated and have restrictions imposed on their daily live due to the negative attitudes and behaviour of the majority of society.

The following section presents the CRG participants' points of view on the negative reality of Indonesian PWD due to myths that have evoked deeply-rooted negative attitudes and behaviour among the general public.

5.1.3.2. Inappropriate attitudes and behaviours toward Indonesian PWD

The CRG participants expressed the view that “*the attitude of the Indonesian people toward person with disability is still deemed inappropriate.* (CRG 8). Based on interviews and discussion with the CRG participants, a range of myths were identified which underpin the inappropriate attitudes and behaviours. Figure 5.1 provides a logically simplified explanation and an introduction before outlining how these concepts are inter-related according to the CRG participants

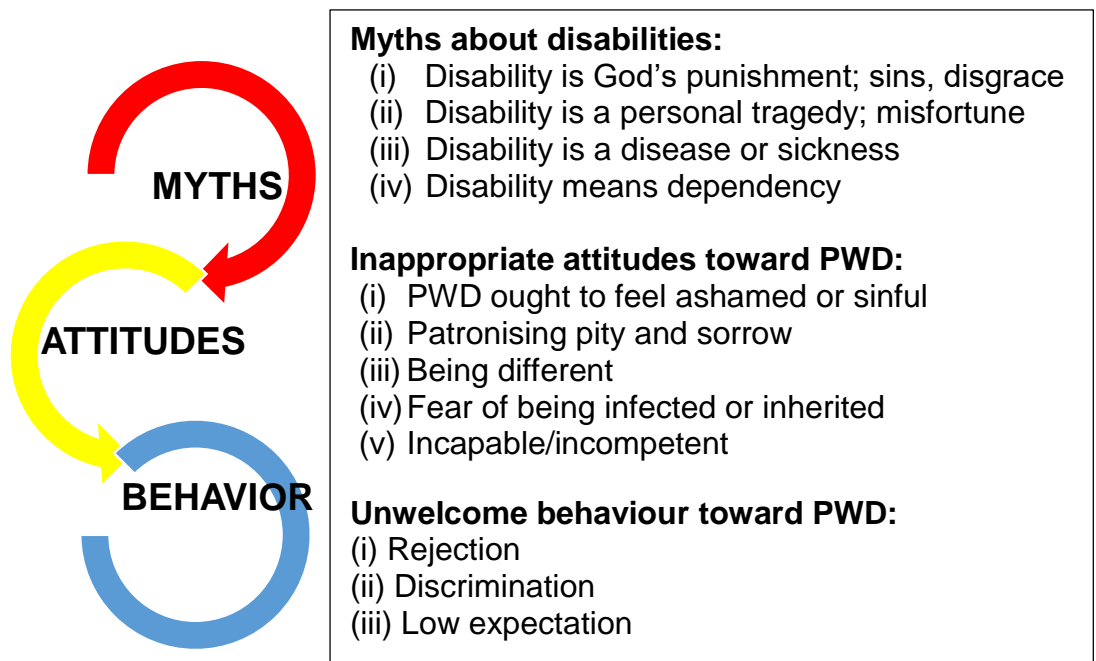


Figure 5.1. Relation between myths, attitudes, and behaviors

Furthermore, with regard to the meaning or definition of the term, another participant explained that: “Attitudes are made up of beliefs and feelings toward persons, things or situations which are often not easily noticed unless presented as overt behaviour” (CRG 5).

Based on the CRG statements above, it appears that according to them, sometimes attitudes cannot be identified clearly but are manifest through people behaviours. Therefore, in this section the CRG participants’ views about the link between myths, attitudes and behaviours are organised under

the prevailing negative behaviours toward Indonesian PWD, namely rejection or exclusion, discrimination and low expectations.

(i) Rejection or exclusion

The CRG participants believed that the prevailing negative behaviours toward Indonesian PWD lead to exclusion or rejection as indicated by the following statements: “PWD generally feel excluded and [they are] not considered as valued members of society”. (CRG 8), “having a physical or mental impairment is really not very pleasant, especially at a young age when you want to have friends and be appreciated, but you received the opposite treatment by your friends or other adults” (CRG 10).

According to the above statements, most CRG members believed that exclusion or rejection resulting from negative attitudes of being different is, for example, not normal, weird, and unwelcome. This could be rooted in the myth that disability is God’s punishment so that having a physical or mental impairment is equal to disgrace, shame or sinfulness. Accordingly, people who have physical or mental impairment are perceived as being different from what is considered to be normal, so that they do not belong or are not accepted as a part of the community.

(ii) Discrimination

According to the CRG participants, it was evident amongst Indonesian PWD that they are “being discriminated [against] just because they have physical or mental impairment (CRG 10), One written description was “...discriminated [against] when participating in mainstream school because of their usage of crutches and a brace, and it was not easy to get access to a a multi-storey building [with] no ramps” (CRG 4, 9/11/2010) “...prevented from joining mainstream schools because I cannot see and read like other ‘normal’ pupils” (CRG 3, 08/11/2010).

The CRG participants also argue that discrimination is imposed upon many Indonesian PWD in the way they are forced to struggle with inaccessible public transportation, as expressed by the following participant

It's very hard to take part in daily life such as going to school or work because of inaccessibility everywhere. Indonesians with disabilities have to survive on their own; they have extra expenses, such as taxis, because they cannot ride on inaccessible public transport”

Based on the above illustration, the CRG believes that discrimination might be caused by several negative attitudes, for example being different and belonging to segregated special education facilities or institutions. These negative attitudes could possibly come from myths that have been identified by the CRG participants presented in Figure 5.1.

(iii) Low expectations

Low expectations of PWD is evident in a number of comments, -for example: “...persons with disabilities were perceived as incapable for attending ordinary school. They should only attend special schools consistent with their disability” (CRG 1).

The above statement shows the negative attitudes toward PWD includes being considered incapable of getting an education in an ordinary school. This results in the discriminative behaviour of excluding them by placing them in segregated educational settings, namely special schools. For the participants, to continue their studies required extraordinary effort because people tended to have low expectations of them.

Another example of low expectations relates to opportunities for marriage, where many Indonesian people might resist approving of a family member marrying a person with a disability. This issue relates to spousal roles and sexuality which are often misunderstood in this context. In fact, sexuality and being in an intimate relationship are aspects of everyday life that are generally misunderstood regarding people with disability. The following participant explained, ‘there is a belief that people with disabilities are a-sexual. People also assume that a person with a visual impairment or hearing impairment is unable to perform their duties as a spouse or a parent’ (CRG 5).

The CRG participants confirmed that these negative attitudes could also arise from the myths about sickness that come from false beliefs about PWD being non-sexual beings, incapable of having sex, loving and being loved. Therefore, this was closely related to assumptions that people with disabilities are incapable of being spouses or parents, due to their impairment being transmittable or inheritable, so that it would become a burden for others in their family and society. They confirmed that these entirely negative attitudes imposed upon them are simply because of the belief that impairment in one part of the body can spread to the entire body – whereas, in fact, other parts of their body and their brains are capable of daily activities or duties. They asserted that this was disputed by the experiences of friends who were in happy marriages and families despite one of the spouses, or both, having some form of disability

Low expectations are also evident in the way that PWD are typecast or stereotyped for specific jobs, as explained by the following participant:

It was common that Indonesians with visual impairments are being stereotyped as masseurs, musicians or singers. Indonesians with hearing impairments are usually associated with hairdressers. The fact is that, I have friends with visual impairment who cannot massage but are qualified computer technicians, website developers, and researchers. I also have friends with hearing impairment who work as a dentist, an architect, and a lecturer. (CRG 5)

According to the above explanation, low and narrow expectations result in stereotyping people with certain impairments as having to perform specific jobs, thus generating restricted opportunities to find other employment. This could possibly arise from a negative attitude in the form of assumptions of incapability rooted in the myth of disability as a personal tragedy, or the myth of disability as a disease or sickness.

In summary, these negative attitudes and behaviours are perceived by the CRG participants as discriminatory and inappropriate because they reflect the

fact that the society is not aware of and denies the fact that they and other Indonesian PWD can be valuable human resources in Indonesian society.

5.1.3.3 Policy insensitivity to disability issues

The CRG participants argued that the laws and policies of Indonesian governments hindered PWD from being equal members in society. One participant expressed that “we can’t expect the laws to be sensitive to the issue of disability if the general public doesn’t know what disability is and how to deal with it”. This means that negative policies are policies that are not inclusive or sensitive to the needs of PWD because they are created by bodies and apparatus without knowledge about disability and how to deal with PWD. This has led to Indonesian PWD facing negative experiences, which has continued until recent times. The apparatus of government is a part of society which still carries negative views relating to disability awareness and insensitivity to their needs.

(i) Insensitive policy response to educational access

The insensitive policies in the area of education are illustrated as follow:

I was prevented from joining the mainstream (regular) school because I cannot see and read like other ‘normal’ pupils. The school principal and teachers said that their school didn’t have facilities to support blind students like me. They didn’t have braille or teachers who understands braille. They seemed to forget that I have a brain and ears to hear the lesson (CRG 3).

According to the CRG participants, as is evident from above statement, Indonesian PWD are discriminated against simply because of their social and physical inaccessibility, which is a result of people’s perceptions and treatment, which are perpetuated by myths. These myths mean people tend to focus only on PWD’s physical impairments and not on the fact that their cognitive capacities are not impaired, and that they are capable of participating in ordinary schools.

For example, there is a public assumption that visually impaired children can only study with help from special teachers and braille letters, which are only available at special schools for the blind. It is neither completely right nor wrong, because visually impaired children can learn by relying on other parts of their body, for example, their hearing and hands. Likewise, children with crutches or wheelchairs can learn without special facilities or teachers. They only have a limitation of mobility. This situation can be dealt with, for example, by minimising the construction of multi-storey buildings or arranging to place them in classes on the ground level.

The CRG participants further explained that insensitive policies are also reflected in interactions where there are the detrimental attitudes and behaviours of individual members of society; for example, school principals and teachers, towards PWD. These attitudes and behaviours are learned and shared in the school or workplace area among stakeholders, such as teachers, pupils, and their families.

Finally, these inappropriate practices and insensitive policies occur because those in the apparatus of government have myths that influence beliefs; for example, the myth that disability is a punishment from God that leads to attitudes of blame for something the person or their forbearers must have done. This then, is also regarded as a difference that is considered as unfavourable and undesirable, so that it may lead to the opinion that individuals with disabilities deserve to be avoided or ostracised. This creates barriers, which manifest in negative practices and policies of segregated schools for pupils with disabilities, perpetuated in turn by social rejection, and limited or restricted opportunities for Indonesian PWD

(ii) Insensitive public transportation policies

Another case of insensitive policies relates to public transportation and physical mobility. Inaccessible public transportation is a major obstacle to PWD living actively in the community. Prevailing negative public attitudes and treatment-based myths are illustrated by the following examples:

I often go alone – like just now when I went by bus; the chair was positioned a bit high and I found it a bit difficult to sit due to the brace for my left foot, so I ask for help to the driver. He helped me but also asked, “Going alone, Ma’am?” in the tone of questioning or even pitying me going alone. Of course I already get bored and annoyed by this question implying a myth in our society that disability means dependency, so that PWD ‘should be’ accompanied, and not go alone in order to not bother others. I was imposed as incapable of being independent by public attitudes, public treatment, and public services [sic.] (CRG 7)

The above comment reflects the immense difficulties related to inaccessible transportation. The participant was upset about being dependent on the help of others. This difficult situation is often experienced when travelling alone on public transportation, where she needs help to get into a bus or other forms of public transportation. This situation made her aware of the public’s expectation that she should not travel alone. It felt like a form of discrimination in that other people with no difficulty using public transportation are not asked about travelling alone !. According to the participant, the prevailing negative attitude is rooted in the myth of dependency.

Inaccessibility to public transportation continues to be a problem since it is not addressed in public policy changes. As a result, the dependency myth fuels the assumption that PWD are always dependent on others. They need to be accompanied and are subject to the help of their closest family, friend or carer. As long as there is always someone to help, public policy tends to ignore the basic rights of PWD to be independent and mobile.

(iii) Insensitive and discriminatory policies concerning employment issues

The CRG participants believed that many Indonesian PWD experience difficulties gaining employment due to discriminatory policies, as illustrated by the case of CRG 9 (as described in the profile section):

...the reason of her failure was not because of academic inability but because she is using a wheelchair... She was rejected because she was

considered non-eligible. Using a wheelchair has been interpreted by the city government as not fulfilling the requirement of being 'physically and mentally healthy.

It is clear that her campus and the city has discriminated against her on the basis of the false belief that wheelchairs are a symbol of sickness and an incapacity to perform a normal job or professional role.

Another participant with a visual impairment also recounted a job-related experience:

We were often confronted with job stereotypes and lower expectation. For example, prospective employers expressed their doubts about the participants with visual impairment who have IT/Information Technology or advanced computer skills since Indonesians with visual impairment are mostly stereotyped as being masseurs, musicians or singers. (CRG 6)

The above circumstances are important elements of the large picture of Indonesian PWD and their social and economic rights, especially from the view of PWD in Indonesia. All of these situations will have implications at the level of public awareness in Indonesia. The CRG members asserted that detrimental policies and real-world situations are closely related to prevailing inappropriate attitudes and behaviours of Indonesian people. The stereotyped and discriminatory perceptions are learned and shared among people in everyday life. All of these factors become internalised and persist in the minds of the public. If the government is sensitive to the needs of PWD, and if policy as a social norm respects PWD, then their lives would be much better, and discrimination, rejection and low expectations would be minimised and possibly change over time.

To summarise the findings related to objective one - the realities of Indonesian PWD life - the CRG participants claim that the existing realities of PWD in Indonesia are still discouraging due to many factors such as discrimination,

rejection and low expectations caused by various myths and insensitive policies. Many Indonesian people still carry negative perceptions that PWD are passive, incapable and a burden on Indonesian society. Myths have led to inappropriate attitudes and behaviours, which have then led to rejection, low expectations and various discriminative practices and policies. These in turn result in the inaccessibility of social and physical environments, which create barriers for the social inclusion of Indonesian PWD. These also show that disability awareness-raising strategies are desperately needed in Indonesia.

OBJECTIVE 2 - Key issues related to the current disability awareness in Indonesia
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These research findings are presented in three sections: negative disability awareness in Indonesia; the goal of positive disability awareness in Indonesia; and finally, the concept of disability awareness. The first section presents the CRG participants' recognition of existing negative awareness among the Indonesian public about PWD. The second and the third sections describe their ideas regarding what is needed in terms of positive disability awareness to respond to negative disability awareness.

5. 2.1. Negative disability awareness in Indonesia

There was general agreement among the CRG participants that **current disability awareness is still based on negative** based on harmful myths and stereotypes as expressed in the following statement: 'current realities of negative disability awareness are happening because the majority of the general public do not have proper and adequate knowledge about what a disability is and who people with disabilities are' (CRG 7).

The CRG participants shared many common views regarding negative disability awareness in Indonesia, which they argue are result of the current format and frequency of disability awareness and disability awareness-raising strategies. They insist that its format and frequency perpetuate existing

harmful myths about disability and PWD, which pose an obstacle to raising positive disability awareness.

a. Events of disability awareness

The CRG participants identified that the current events and formats of disability awareness in Indonesia were narrowly focused on an annual ceremony to celebrate International Disability Day on December 3. Sometimes it is also accompanied by a public campaign in the form of: 'special articles or reports in magazines or newspapers, or TV shows highlighting disability issues or featuring Indonesian PWD' (CRG 1 and CRG 2), 'an exhibition of art pieces by Indonesian artists with disabilities' (CRG 4), 'sport events for Indonesian PWD who love and are able to do certain sports, or sport competitions such as the Paralympics by Indonesian athletes with disabilities' (CRG 5).

However, the existing format was criticized by the CRG members in the following ways:

There is a weakness in Indonesia's current disability awareness strategy of an annual ceremony on December 3 - the International Disability Day where a majority of the audience is the PWD community. It should be emphasised to the general public, which is actually the main source of social exclusion and all kinds of discrimination experienced by Indonesian PWD—and therefore, needs to be educated about disability [sic.] (CRG 9).

Wayang/shadow puppet plays, which are known for their ability to deliver the vital concept of harmonious living between PWD and non-PWD until recently, can only reach a limited number of people—who have a genuine interest in wayang, such as certain ethnic groups—and, consequently, cannot reach a larger public (CRG 4).

There are also written campaigns such as magazine or newspaper articles, but those can only be appreciated by those who are literate, enjoy reading and can afford to buy the printed publications (CRG 1).

Other forms include a rally of PWD to protest against certain issues. This is often partial and local, and so far, there has not been a significant rally organised by the national disabled community of Indonesia which may raise awareness with regard to what Indonesian PWD need, or fight for. In comparison, we can look at the rallies of the disabled community in the US or England, which have been able to create significant changes and legislation, such as the Disability Discrimination Act, which was the result of united efforts and accommodates a range of important needs of the disabled (CRG 7).

Finally, in contrast, they asserted that it should be conducted in a format that makes it possible to reach a wide cross section of the population, as described by the following participants:

...[awareness-raising] needs to be done on a big scale, such as a public campaign or national rally, so that other people can be aware of what it means to be disabled, who the people with disability are, and also that people with disabilities are part of society (CRG 7).

There is no single way to raise awareness of disability, but it would be good to develop a programme via electronic media, such as videos. Indonesian people are more attached to audio-visual media than written media, such as newspapers or magazines (CRG 1).

b. Frequency of disability awareness

The majority of the CRG confirmed that disability awareness in Indonesia has to be conducted regularly, on an ongoing basis, and be sustained. They considered this to be critical in order to address its current reality, which centres around an annual event associated with International Disability Day.

This was expressed by several CRG members: 'Disability awareness-raising actions are very limited, and are only highlighted on International Disabled Day and contained locally. It should be implemented continuously' (CRG 9). 'Currently, disability awareness is only done incidentally and lacks careful consideration of what the impact is and what the next action is' (CRG 4). The

reason for this was stated by the following participant: “People easily forget when it [awareness] is not done regularly and continuously. It was necessary, so people can be reminded all the time” (CRG 10).

5.2.2. The goal of positive disability awareness for Indonesia

There was general agreement among the CRG participants to change the existing negative awareness based predominantly on harmful myths and assumptions: “current realities of negative disability awareness are happening because the majority of the general public do not have proper and adequate knowledge of what a disability is and who the people with disabilities are” (CRG7). A CRG member also agreed that disability awareness was closely related to activities or programmes, as indicated by the following statement: “Disability awareness programmes and materials are to educate the society about disability and people with disabilities” (CRG 1).

Based on the above statement, the CRG participants argued what was needed to change the negative into a positive was education. This is because they perceived education to be a deep and broad concept consisting of providing information, knowledge and values.

There was also general agreement among the participants that the “goal of disability awareness is to ensure people have positive perspectives and attitudes to persons with disability, and disability awareness programmes and materials, which are intended to change the mindset of people in our society about those who are people with disabilities, what disability is and the policy regarding disability.” (CRG 3)

Very clearly here, according to the CRG participants, educating people includes enabling people to have a good understanding of disability, and people with disabilities; adopting a positive attitude toward people with disabilities; and a willingness to consider people with disabilities as having equal rights and capacities.

The principle goal of disability awareness is described as being the capacity to respond to the key problematic issues caused by negative attitudes, behaviours and policies that are predominantly based on harmful myths.

5.2.3. The concept of disability awareness

The participants identified acceptance as a key element of disability awareness. They viewed disability awareness as a pre-condition for public acceptance of Indonesian PWD. Thus, what is needed to counter the existing negative disability awareness is an acceptance that Indonesian PWD are part of Indonesia's diverse society. Indonesian PWD have needs, rights and capabilities, and the acceptance that they can contribute to society. In other words, an acceptance of positive attitudes toward disability and PWD needs to be a fundamental part of the strategy to address existing negative realities. Explanations of the five key components of awareness strategies are presented in the following sub-sections.

a. Acceptance as part of diversity

In describing diversity, the CRG participants perceived disability as a natural part of diversity that exists in life, such as people having diverse physical appearances, dialects, personal beliefs, and so on. CRG 10 stated that: '... human variation could be skin colour, hair style, difference background: culturally, religiously, ethnically, racially, and also in ability namely the ability to walk, ability to see, ability to handle things and also other types of physical characteristics' (CRG 10). Accordingly, 'disability awareness is a state where disability is seen as a part of diversity, [similar to] differences in dialect, ethnicity, skin colour, hair, etcetera; where society accepts people with disabilities as part of their entity, where no discrimination against people with different appearances [exists]' (CRG 2).

The CRG member revealed that the existing negative disability awareness occurred due to the fact that the Indonesian public has not accepted the idea that Indonesians with disabilities are part of the diversity of everyday life. Damaging beliefs, which have caused bad and detrimental images amongst

the Indonesian public, have prevented them from accepting the fact that individuals with a disability are human beings. They are more alike than different from other human beings with visible impairments. Indonesians with disabilities suffer ill treatment because of the existing myths that are socially transmitted from generation to generation. This CRG member suggested that the community's understanding need to be changed, and that the differences are not abnormal, but a typical part of the diversity in the world. This can be done by providing and always emphasising the tangible evidence of the sameness or similarity of Indonesians with disabilities compared to other Indonesians.

b. Acceptance of the needs of PWD

The CRG participants explained that disability awareness involves the public accepting the needs of Indonesians with disabilities so that they can live like all other people:

There is little awareness because nobody cares [about] the needs of people with disabilities. People with disability need to go to public spaces and take part in society as much as they can. It's very hard to take part in daily life such as going to school or work because inaccessibility is everywhere. Indonesians with disabilities have to survive by themselves; ... have extra expenses such as for taxis because they cannot ride on inaccessible public transport; or to pay somebody to assist them for mobility or to access buildings. The situation would be different if there was accessibility (CRG 7).

The participants explained that the Indonesian public are still not aware that Indonesians with disabilities have many needs in common with other members of society and want the right to have such needs met. This has caused PWD to be marginalised by restricted opportunities. Their need for control and choice is ignored because of negative practices and policies, which do not take into consideration their needs and wellbeing, thus perpetuating the cycle of inequality.

Therefore, the CRG believe that it is necessary to change the public mindset that Indonesians with disabilities are lesser people than other Indonesians. They have the same needs and should be treated like anyone else; they need to be appreciated and respected; and they require an equal opportunity to fulfil their needs.

c. **Acceptance** of the **rights** of persons with disabilities

According to the CRG participants, positive disability awareness is basically a condition where the rights of Indonesian PWD are accepted by the public. This is so they are:

...aware that people with disabilities do have rights and their rights are the same rights as other people without disability. They have to be given the same opportunity and probably even more affirmative action to assure that they can enjoy their rights (CRG 10).

However, most of participants of this study further revealed the current reality where their rights were neglected. According to them, this happened due to false beliefs, which came from a broad public misunderstanding about disability and PWD, as described in the earlier section. They illustrated some of their rights that often to be neglected by the public as follows.

(i) The right to be independent and have choice

This was expressed by participants in this way: 'It is necessary that people with disabilities be accepted everywhere and have choice in their lives. They should not be confined to living in institutional or special schools' (CRG 1).

As outlined in an earlier section, the negative behaviour of segregation reveals that society is unwelcoming of PWD, and mostly not aware that PWD are member of the society who have the same rights. Accordingly, participants indicate that most Indonesians PWD are deprived of the right to have choices. They observe and note many example of this deprivation, such as the fulfilment of the right to have a decent place to live and to go to school, as well as the availability of choices related to accessing work, transportation, and so on.

(ii) The right to engage in spiritual or religious activities

Another illustration of the current condition relating to Indonesian PWD's right was clearly described by the following participant:

All public worship places are inaccessible. I have argued with the religious officials who said that people with disabilities are considered as sick people who are not obliged to pray in jamaah in the public worship place. We are not sick people! We live with our disabilities throughout life! God creates us with the same rights. We have the same rights to be able to pray in public worship places as other people (CRG 5).

Therefore, the CRG members insist on the need to change the public mindset to one which accepts that Indonesian PWD have inherent rights. Indeed their rights are guaranteed by law and the public have obligations and responsibilities to provide the opportunity for them to enjoy their rights.

d. **Acceptance of the capabilities** of PWD

Disability awareness is a condition where people with disabilities are accepted as having capabilities despite their impairment. This was clearly explained by the following participant:

Although having impairments, people with disabilities have capabilities, even creativity, to do their daily activities which are sometimes different from others who don't have impairments. For example, although I have a visual impairment I am still able to read. I read with my fingers by touching Braille or with my ears when I hear JAWS (a screen reader software), reading all [that is] written on my computer screen'. Another example of creativity is others with paralysed legs who then modify bicycles to be used by hand rather than by foot (CRG 3).

This explanation clearly attenuates the dominant negative awareness toward Indonesians with disabilities arising from the belief that Indonesians with disabilities are incapable, inferior to others, and a burden to their family and society.

There was general agreement among the CRG that one of the key strategies for positive disability awareness is to disseminate evidence of their abilities in order to change public perceptions, which are mostly based on damaging and misleading myths.

e. Acceptance of the contributions of PWD

According to the CRG participants, one of the key ways to address the existing negative disability awareness in Indonesia is to foster the acceptance that Indonesians with disabilities are able to contribute to their community and that their contributions are respected. The CRG participants described their contributions to disability awareness in Indonesia despite several challenges or limitations:

There are a number of [Indonesian] scholars with disabilities that have concern and have contributed to disability awareness programmes. Some of them successfully endorse particular programmes on a local level due to limited resources and support from surrounding people, especially the government (CRG 9).

I have worked together with a disability activist from a Disabled People Organization (DPO), since last year, to develop a disability training model for local government officers from five districts in Yogyakarta. We managed it among our dissatisfaction on the lack of enforcement between policy and the budget of the government for disability awareness programme [sic.] (CRG 8).

In summary, the key issues related to current disability awareness in Indonesia, that CRG participants described were that there is currently negative perceptions of Indonesian PWD arising from the belief that Indonesians with disabilities are a burden and not an integral part of society due to their perceived incapacity to contribute to their society. This is closely related to issues with the current format and frequency of disability awareness-raising strategies, which are not sufficient in raising positive disability

awareness in a sustained and large scale manner. The participants believe that positive disability awareness would be discernible when people accept the ability and values of Indonesians PWD and give them equal opportunities to participate and contribute to society.

As described in Chapter One, this research was motivated, among other things, by the action of the DSC-UI's disability awareness-raising strategies, which involve the use of disability awareness training videos. However, there was an expression of dissatisfaction from the CRG that existing videos cannot be classified as disability awareness videos. Furthermore, based on the literature and material reviews, there were no disability awareness videos available in Indonesian. These all indicate that the most needed disability awareness-raising strategy is a disability awareness video. Therefore, this study has explored this idea, in collaboration with the research participants, because they know best the needs of PWD.

The following section describes in more detail the aspirations of the CRG regarding the most appropriate disability awareness-raising strategy in Indonesia and its development.

Objective 3 – The development of a disability awareness video as a disability awareness-raising strategy proposed by the research participants.

This section describes the research findings related to the third research objective, and is organised into three sections:

1. **The participant's aspirations for a disability awareness video section,** which comprises three sub-sections. Firstly, the decision that videos are the best strategy for disability awareness-raising (based on the aspirations and advice of the participants) is discussed. Secondly, the challenges associated with enhancing positive disability awareness in Indonesia are presented. There are challenges to developing disability awareness videos in Indonesia which include limited and negative public understanding of

disability and shortcomings in resources. Thirdly, the methods of developing a disability awareness video for Indonesia are presented. In their description of the video production method, the CRG mentioned a range of issues which could serve as guidelines in generating a disability awareness video for Indonesians. These covered the target audience, the type, duration and theme of the video, the actors, as well as the contents, which cover the purpose and message of the video.

2. **The video development process section** includes three stages: the pre-production stage (budget, working time for video production and the operationalisation of the CRG video guidelines); the production stage (video-making process) and the post-production stage (the first, second and third edits: feedback from DPO member participants and undergraduate student participants).
3. An illustration of the disability awareness video developed in this study.

5.3.1 The participants' aspirations for a disability awareness video

5.3.1.1 Video as the preferred strategy.

Based on the interviews and group discussions, the CRG agreed that the most accessible format for creating positive disability awareness is videos. They asserted that video, as a disability awareness-raising strategy, offers both images and audio to counter the existing negative public understandings of disability and Indonesian PWD. Therefore, they believe that videos have the capacity to present meaningful examples to reject deep-rooted negative beliefs that are perpetuated through intergenerational internalisation. Videos offer a visualisation of disability and Indonesian PWD, which are easier to understand and more readily accessible than written descriptions or an oral explanation. They also may be widely circulated to have a greater reach. Their reasons are further shown by their statements below:

There is a public campaign in the form of an exhibition of art pieces by Indonesian PWD, but these are often incidental as they are often held only on the International Day of People with Disabilities, where the

public is able to appreciate the works but forget the meaning of the campaign after it is over” (CRG 10)

Other forms include a rally of PWD to protest against certain issues. This is often partial and local, and so far there has not been a significant rally organised by the national disabled community of Indonesia which may raise awareness with regard to what Indonesian PWD need, or fight for. In comparison, we can look at the rallies of the disabled community in the U.S or England, which have been able to create significant changes and legislation, such as the Disability Discrimination Act, which was the result of united efforts and accommodates a range of important needs of the disabled (CRG 7).

Moreover, one participant claimed that

Art exhibitions, sport events or competitions, rallies and wayang (Indonesian traditional puppet plays) have another weakness: they cannot be viewed repeatedly, unless documented in audiovisual form. In reality, this is rarely done and the said forms are rarely broadcasted to the public at large (CRG 5).

Based on the weakness of the existing format of disability awareness raising, it is obvious that the research participants regard video as the most appropriate format for a disability awareness-raising strategy.

The following sections are descriptions of the challenges to and methods of developing a disability awareness video, as identified by the participants.

5.3.1.2 Challenges to developing an appropriate disability awareness video in Indonesia

In the second interview list of discussion points, the CRG participants were asked to describe their opinion about the facilitators of or barriers to developing disability awareness video in Indonesia. During the interviews, they found these questions did not capture the circumstances. Instead they suggested to

discuss challenges rather than merely the facilitators of or barriers in developing video. They argued that the discussion of challenges would serve as a reminder of some matters that needed to be recognized and anticipated. This means that any matters which currently might be seemed as negative are needed to be anticipated during the planning of video producing so that they do not become barriers. In contrast, when any matters which currently looked positive, they still need to be kept in mind so that they can be used as supporting factors, and not become counter-productive for video development process. For example, a dominant opinion related to video production is limitation of finance is considered as a barrier to developing widespread awareness-raising strategies.

Hence, from the interviews and discussions, all of the CRG participants agreed that it would be possible to develop an awareness video for the Indonesian public with the interests of PWD in mind. However, project participants acknowledged that this initiative would face challenges. Producers of awareness-raising media need to consider two main elements; namely the public understanding of disability, and the resources available to Indonesian PWD.

a. Public understanding of disabilities in Indonesia

The CRG participants sometimes used words like 'mindset' and 'paradigm' to talk about what I am broadly characterising as public understanding. In this section, these words refer to the way the Indonesian public understands and perceives Indonesian PWD, as well as disability in general.

The CRG participants explained that negative public understanding caused by damaging myths was a challenge in the making of disability awareness videos. They argued that these myths have made the lived experience problematic among Indonesian PWD due to 'ignorance [being] bigger than [disability] awareness [and that] taking responsibilities has not been within the culture of the policymakers in Indonesia' (CRG 10). Apparently, according to the participants, this problematic experience relates to the public understanding

that 'impairment and disabilities are disadvantages of someone that will not happen to others' (CRG 2) and as such, 'disability is not my business' (CRG 3).

In the previous section, four dominant myths were identified by the CRG participants, namely that disability is God's punishment; a personal tragedy or misfortune; a disease or sickness; and that disability means dependency. All these damaging myths have been described as the cause of negative public understanding which makes the life of PWD in Indonesia more difficult or problematic. Therefore, we agreed that these realities are the reason why raising positive disability awareness among the Indonesian public is important.

According to the CRG participants, those dominant public understandings of disability were seen as a major challenge to awareness raising. If not recognised and anticipated, it could become a real barrier to building new and positive awareness. The Indonesian public would likely be disinterested in the disability awareness programme, because they would consider disability to be an issue irrelevant to their lives. This would result in the public rejecting responsibility for caring about the experiences of Indonesian PWD and rejecting the need for social change in this area to foster a more progressive and accepting understanding of disability. Consequently, according to them, the disability awareness goals would be impossible to achieve in such an instance.

Therefore, participants explained further that in order to counter public negative understanding, our challenge in the making of a disability awareness video was to encourage new understandings of disability and people with disabilities:

The public needs to understand that impairment and disabilities can happen to everyone, at anytime and anywhere. Disability is a complex issue often combining varied physical and social conditions in the environment where Indonesians with disabilities live alongside open

discrimination and oppression, such as lack of access to mainstream education, work and transport (CRG 2).

One of the CRG members also highlighted further challenges in disability awareness raising. This was related to the public perceiving them as objects of pity, and in need of help from charity or philanthropy programmes, which are mostly considered religious deeds. This was illustrated by the comment: 'a small number of PWD sometimes take advantage of the public based on the 'personal tragedy paradigm', where persons with disabilities can be a source of religious charity' (CRG 2). For the CRG 2 and also the majority of the CRG participants, this was considered a challenge. The interpretation that PWD are the source of religious charity is not constructive enough. It is also not in accordance with the spirit that PWD are capable and are not dependents who need to receive donations from religious deeds. Furthermore, the above-mentioned interpretation might lead to reluctance to become activists' awareness amongst Indonesians PWD who accept this false understanding or interpretation.

b. Resources

All CRG participants agreed that a positive disability awareness approach should be pursued. However, they also acknowledged that there was a big challenge to developing a disability awareness video due to limited finances being available for such projects and programmes. This was described by opinions such as: 'It is not easy, especially related to financial limitations' (CRG 1), because 'it will need financial resources, skill and knowledge on how to make a good and effective campaign' (CRG 7).

Nevertheless, they also agreed that limited financial resources must not prevent the implementation of positive disability awareness-raising strategies. They generally believed that there are strong potential resources to develop more appropriate disability awareness (DA) programmes and audio-visual materials due to 'the significant number of disabled scholars who are concerned and willing to contribute to the planning, and designing of DA

programme materials' (CRG 5; CRG 6 and CRG 9). It was clear that according to them, the existing scholars and activists with disabilities, and organisations of PWDs were considered to be resources. 'It is possible by working together with disability activists from DPOs, as during my experience since last year, 2009' (CRG 8), 'because in fact, several DPOs, despite facing financial difficulties, have tried to create a public campaign on disability in their area with very minimal resources' (CRG 2). They also believe that this potential will be even stronger 'if DPOs are united and work together, not separately' (CRG 7).

The CRG participants' aspirations and optimism with regard to dealing with limited resources is clearly manifest in this research project, for they have provided expertise, guidance, and dialogue as important components of the process. Collaboration among researchers and participants has enabled us to develop stronger commitment and more fruitful efforts in this study.

The next section presents the findings related to their ideas on developing a disability awareness video.

5.3.1.3 Methods to develop the disability awareness video for Indonesia

To address the current negative realities of Indonesians with disabilities, the CRG participants' aspirations included developing a positive image that disconfirms or challenges current Indonesian attitudes and beliefs. Their ideas about how to do this were incorporated into the video production methods, which covered several elements. Details of each element are described below.

a. Target audience

All CRG members shared the view that the target audience for the disability awareness strategy should be the general public. This would help to more effectively address the problematic issue of how Indonesian PWD and disability in general are viewed in Indonesia. Furthermore, in order to have the greatest impact, they all argued that disability awareness raising should be delivered to the younger generation through educational institutions, including schools, colleges or universities. This was based on the reality that negative awareness about disability and Indonesians with disabilities was rooted in

damaging myths which were internalised from generation to generation. Therefore, young people were the main target audience in order to achieve inter-generational change. This was illustrated by such aspirations: “disability awareness has to be part of the curriculum of schools and also help professional education” (CRG 10) ... “so that they can behave appropriately [toward Indonesians with disabilities]” (CRG 8). They revealed that such strategies are expected to broaden young people’s understanding of disability and PWD so that they will have a shift in values, attitudes and beliefs, which will result in them behaving respectfully towards Indonesians with disabilities when they graduate and enter the work force.

However, all participants acknowledged that this study had time and budget constraints. As one CRG member mentioned: “a wide range of materials should be prepared for different targets. This means the material should be customised with each target, for example material for primary schools cannot be generalised with material for undergraduate university students” (CRG 9). Therefore, for the target audience, it was decided to focus on undergraduate university students. As the CRG participants expressed: “our project can start with a campaign or training; with the target group being undergraduate students and staff in universities” (CRG 4). This approach has been agreed upon based on ongoing disability awareness training initiated by the DSC (as described in the research process section), and on the fact that the university was supportive of this study.

In addition, all participants also acknowledged that the actual target of disability awareness raising was the general public, which also includes people with disabilities. This was due to the complexities of disabilities issues, in which having one disability, for example, visual impairment, does not mean the person is an authority on other kinds of disability; for example, hearing impairments, intellectual disabilities, and so on. This is especially the case if “they were raised in over-protective families and were socialised in special education” (CRG 1). Therefore, the participants emphasised that the video should be developed for and accessible to a wide audience.

b. The format of a disability awareness video

The CRG participants shared many common aspirations regarding the format of a disability awareness video, which closely relates to the type, duration and theme of the video to be developed.

There was general agreement among the CRG that a video was the most accessible and engaging format to raise positive disability awareness to as wide an audience as possible in Indonesia. They believed that video has the capacity to improve people's understanding about the lives of people with disabilities. Visualisation of meaningful aspects of life, both image and sound, in a way to accommodate the voices of people with life experience of disability in Indonesia was considered invaluable. It is important to deconstruct deep-rooted negative beliefs that are perpetuated through intergenerational internalisation.

There were aspects that emerged from interviews and discussions with the CRG participants relating to the video format. These included the type, duration and theme of the video to be developed in this study.

(i) Type of video

The CRG participants argued that the disability awareness video to be developed should be non-fiction and should serve as a 'Public Service Announcement (PSA) that should be made to promote a particularly important idea or concept to the public, but not to commercially offer any products' (CRG 4), and take the form of a 'semi-documentary' (CRG 5 and CRG 8). This format would function as audio-visual material in disability awareness programmes, such as training programmes or campaigns.

The CRG gave an example of a PSA video on littering which explains the concept of reduce-reuse-recycle, and the importance of separating organic from non-organic rubbish. Therefore, a PSA relating to disability, among other things, would be concerned with accessibility for wheelchair users, and would explain the purpose, as well as examples, of the accessibility required. The basic characteristics of a PSA is its short duration (usually less than 5 minutes)

and the content focusing not on the personal story of an individual, but rather on a particular idea or concept. The basic characteristic of a documentary is telling a factual story, either an episode or story which is told directly by the subject or by the related party. Usually, a documentary has a longer duration than a PSA, but is shorter than most films; that is, more than 15 minutes. Finally, the CRG agreed that the type of disability awareness video to be developed for this project was to be a semi-PSA and semi-documentary. The intent, then, was to convey the most important concepts related to disability and the lives of people with disabilities, and for this to be directly delivered by Indonesian PWD in a short documentary.

(ii) The duration of the video

It was clear from the discussion with the CRG participants that the type of video is closely related to the duration. With regard to their description of this, they further asserted that the estimated duration of the video for this research project should be around '10-15 minutes' (CRG 8) '... the common duration of scientific seminars or conference presentations' (CRG 7).

(iii) The theme of the video

Discussions with the CRG also reflected the type of video in terms of themes. There was general agreement that the main theme of the video was to be equality: '... about equal rights messages which portray the daily life of persons with any disabilities, ... their struggle to access their basic needs; for example, education, health care, employment ...' (CRG 8). This was based on the fact that one of the core problems of negative disability awareness in Indonesia according to the CRG was the inequality experienced in the daily lives of Indonesian PWD.

c. Actors

The CRG participants considered that it was imperative that PWD be involved as central actors in developing disability awareness programmes including the proposed video. As CRG 9 stated, "it must involve people with disabilities in

designing, planning, conducting and evaluating disability awareness. It needs to mainstream disabled people's issues" (CRG 9).

They addressed the disappointing realities of disability awareness in Indonesia, and mentioned that this was due to the absence of PWD involvement, as expressed by the following participant: "because they don't consult with us, the media (electronic and printed media) often deliver wrong messages about disability that is such exploitation of the pity of PWDs, or otherwise shown them as superhuman [sic.]" (CRG 5). In other words, thus far, the visualisation of disability or PWDs has not been not based on them as appropriate sources but has relied on the damaging myths or beliefs which in turn have reinforced negative public understandings.

In contrast, they asserted that their lived experience is an important resource which can offer appropriate knowledge, as indicated by CRG 6: "the development of disability awareness materials should begin with a clear direction and letting people with disabilities themselves develop such concepts".

Therefore, the CRG participants insisted that, in this study, Indonesian PWD should be the actors or central figures in developing the awareness-raising video, and not non-disabled actors or the producer. This meant that they had to play active roles. They should directly voice their ideas or express the message about living with disabilities. This argument was based on the fact that they found that PWD oftentimes were passive in video production; and presented in a passive role in videos posted on online websites that are tagged as 'disability awareness videos'.

d. Content

The CRG participants indicated a strong link between the content of disability awareness videos and their purpose. They emphasised that a disability awareness video is intended to educate the target audience through its content with voices directly spoken by the actors with disabilities.

d.1 purpose

There was general agreement among the CRG that the purpose of the disability awareness video was to be a form of educational material enabling people 'to have a good understanding of disability and people with disability; to adopt a positive attitude toward people with disability; and to have the willingness to treat people with disabilities as having equal rights and capabilities' (CRG 1).

d.2 message

It has been identified from discussions with all participants that in order to meet its purpose, the contents of the disability awareness video should consist of three core messages, namely informative, instructive/educational and affirmative messages. They considered these to be the most significant aspects which would distinguish the video produced for this study from others produced and published on websites that claim to be, or are tagged as, disability awareness videos.

This decision was based on their observation that the commercial videos and the online videos on free website generally contained only one of these three messages. For example, these videos generally conveyed informative messages in the form of personal stories of PWD or documentaries on their activities or achievements. There were some videos which contained instructive messages, but these were communicated directly by public figures who were the main cast, while PWD had given a 'passive role' (CRG 4) or were portrayed as 'helpless objects' (CRG 8) who were not given the opportunity to speak. Thus, according to the CRG, these were not disability awareness videos. Details of each message are described in the following section:

(i) Informative message

Informative messages were believed by all participants to be one of the important contents of a disability awareness video, whose purpose is to enable people to have a good understanding of disability and PWD. The CRG members identified a range of messages, such as: 'knowledge of disability,

namely, among others, various types of disabilities, the cause of disabilities, the theory of disability, and the rights of persons with disability' (CRG 3). 'Disability is a part of society that cannot be separated from social dynamics, everybody in society at any time can become disabled' (CRG 2). 'There is a variety of impairments and roles of PWD in society' (CRG 9). 'There is a variety of activities PWD conduct in their daily lives which they struggle with; for example, using public transportation to public services (CRG 8). The 'variety of age, religion, ethnicity, and social economic status of PWD; (CRG 2). 'Persons with disabilities are ordinary people, not pitiable, not a burden; nor are they superhuman or extraordinary' (CRG 1). It was also expected that the message of the video would also be able to cover messages such as 'the meaningful presence of persons with disability in society, both for the person with disability and for the society' (CRG 1), and that 'disability is an inter-sectoral social problem not a personal tragedy' (CRG 2).

All these informative elements provide a reliable illustration that Indonesians PWD have many similarities to general members of society who have no disabilities. Thus, the informative messages are intended to disconfirm negative myths and paradigms of disability which have created negative public attitudes and behaviours where Indonesians PWD are excluded and discriminated against.

(ii) Instructive/educational message

It was considered imperative by all participants that instructive/educational messages need to be the central content of a disability awareness video to counter the key problematic issue of the barriers Indonesians with disabilities experience. This was clearly illustrated by the following participant:

Actually there is no such information or education or training at home or in school to educate the public about disability. No programmes in public TV, radio, or printed media on how to deal with persons with disabilities appropriately and respectfully (CRG 10.)

There was general agreement among them that the instructive/educational message consist of three main elements: “How to interact with people with disabilities. How to communicate with people with disabilities. How to help people with disabilities” (CRG 1, CRG 3). Some of the CRG members added explanations such as: “For examples, how to walk with blind people, how to communicate with the deaf, how to have social interaction with people with autism, and so on” (CRG 3). “How to communicate and to help wheelchair users” (CRG 5). Additionally, one participant emphasised that “there are techniques that are required for each disability and general etiquette to help people with disabilities” (CRG 8).

All these instructive/educational messages were intended to enable the audience to adopt a positive attitude toward people with disabilities; and to have a willingness to treat people with disabilities as having equal rights and capabilities.

(iii) Affirmative messages

The majority of participants considered affirmative messages to be crucial content for a disability awareness video. These messages express respect, approval and confirmation of positive awareness about disability and PWD. They are urgent and essential in order to disconfirm negative myths and paradigms of disability that have been held by the majority of the general public in Indonesia until recently.

The affirmative message includes a range of examples, such as: “Helping people with disabilities is our social responsibility. Remember, we all have the same rights” (CRG 10). “Accessibility is a PWD right. Providing an accessible and friendly environment not only benefits people with disability but also many other people such as senior citizens, pregnant women and children” (CRG 3). “I am the same - just like you and you are different - just like me” (CRG 5). From discussions with the participants, what also emerged was an agreement that the affirmative message should be exemplified by using what CRG 5 offered as the title of the disability awareness video developed in this study. It

was agreed that the phrases 'I am the same - just like you and you are different - just like me' 'be an affirmation of the uniqueness of every human being, and that Indonesians with disabilities are human beings who are more alike than different from other Indonesians.

The above-mentioned descriptions were the CRG members' aspirations to develop a positive image that dispels or challenges current Indonesian attitudes and beliefs. Their detailed aspiration of the disability awareness-raising strategy involved disability awareness media production methods. These methods covered at least eight elements:

- 1) The target group is the general public, especially the younger generation. However, due to this study's limitation, it focuses on undergraduate students.
- 2) The media type is a semi-documentary and semi-public service announcement (PSA). This means that it would be a non-fiction, realistic representation of PWD.
- 3) The media format is a DVD, which would be used in disability awareness programmes as part of training programmes and campaigns.
- 4) The media duration should be around 10-15 minutes.
- 5) The actors have to be PWD who act as themselves in their daily routines, and the media should also involve their significant others.
- 6) The media should function as educational material to enable people to have a good understanding of disability and PWD; as well as support the adoption of a positive attitude toward PWD, and a willingness to behave appropriately with PWD.
- 7) The main themes are non-discrimination and equality, which frame the contents of the media.
- 8) The media must consists of three core messages: informative, instructive/educational, and affirmative messages.

The main aspirations of the CRG participants have been briefly summarised in Table 5.1. This table lists the elements of a good disability awareness-raising strategy for Indonesian people. The CRG agreed that this list would serve as

guidelines for developing a contextually appropriate disability awareness video in this study.

Table. 5.1. The CRG guidelines for a disability awareness video

Elements	Explanations
Target	Non-disabled undergraduate students
Type	Semi Documentary and semi Public Service Announcement, non-fiction
Media Format	DVD (digital video disc) – optical disc, to be delivered in disability awareness programme such as a training programme or campaign
Duration	10 – 15 minutes
Actor	PWD as the central figures who act as themselves in daily life and non-PWD (their significant others).
Purpose	As an educational material to enable people to: <ul style="list-style-type: none"> • have a good understanding of disability and PWD; • adopt a positive attitude toward PWD; • willing to behave appropriately with PWD.
Theme	Non-discrimination and equality
Content	<ol style="list-style-type: none"> 1. Informative message, includes: <ol style="list-style-type: none"> a. Knowledge on disability b. Disability as a part of diversity and social life in society c. The rights of PWD; d. The variety of roles of PWD in the society e. The variety of activities of PWDs in their daily lives 2. Instructive/educational message, includes: <ul style="list-style-type: none"> • How to interact with PWD. • How to communicate with PWD. • How to help PWD. 3. Affirmative messages, include: <p>Confirmatory, favourable and positive messages expressing respect, approval and confirmation of positive awareness about disability and PWDs, at the beginning and end of every visualisation.</p>

This is the end of the detailed description of the CRG participants' aspirations regarding challenges and methods of disability awareness-raising to promote a good image and positive awareness of disability and PWD in Indonesia. The next section presents an account of the video production.

5.3.2 The disability awareness video production process

This study achieved the third research objective despite some unexpected incidents, such as changes to the technical production team, refusal of some nominees to be video participants, unfriendly weather, and timing difficulties (as described earlier in the section on the research process). The challenges will be elaborated on later in this section.

Producing the video was very challenging due to unexpected incidents, especially with changes to the technical crew. The development process was finally able to start after consultation with the CRG participants and support from the Dean of Faculty of Social and Political Sciences, University of Indonesia, who provided assistance by allowing students majoring in broadcasting in a vocational program at the university to participate as part of their video production work experience.

The video was the end product of a collaborative process representing:

- what the CRG participants and I regarded should be the content of the disability awareness video;
- the video participants' ability to express their experiences, needs and interests in the shooting process so as to be in line with the goal of disability awareness videos; and,
- the broadcast student production crew's ability and technical skills.

The key outcome of this video production was that the aspirations of the Indonesian PWD who participated in this project were captured in the disability awareness video. These outcomes appear in the post-production stage, the final and most challenging stage of the three-stage video development process which involved pre-production, production and post-production stages. The findings from each of the three stages are presented below.

5.3.2.1 The Pre-production stage

The crew explained that this stage principally contains the preparation of the technical aspects for video production. This stage officially started by meeting two student crew members to discuss the details. It was the day after our first meeting, which was facilitated by the Dean, where we were introduced to each other and they agreed to help me after I briefed them on the intention of the video and my research. I asked the crew about the details of technical video preparation, as this video project was my first such experience. Consequently, as part of this process, I learned a range of broadcasting terms and roles involved in making a video. This included the term ‘talent’ to describe the actor or cast while, for the purpose of thesis writing, it refers to video participants. Discussions with those involved was a complex process, and both the crew and the researcher tried to learn from and adjust to each other. I learnt that the first and most important concern of this process was the tight budget and working time for the video production, which was then associated with the number of students in the crew and their job description.

a. Budget and working time for the video production

In discussions with the crew it emerged that there was a high cost attached to renting filming equipment and the crew’s fee. This cost was unanticipated because, formerly, the video was to be produced by a local TV crew. On the other hand, the student crew had several commercial clients who paid them a fee. It was also apparent that the crew assumed that this project was sponsored by the Dean, when in fact it was not. I was only relying on my fieldwork allowance to fund this video project. I emphasised that the estimated time was eight weeks with the budget based on the remaining time of the second field trip and the remaining two years of my fieldwork allowance, which was AUD 1400 a year. Therefore, there was a very limited budget available, which was much lower than was needed to make the video. Consequently, we tried negotiating the fee with the crew due to the fact that this was not a commercial project but a research project for my thesis. Other factors impacting the video production were the remaining time of my fieldwork, the upcoming month of Ramadan which could affect production, and the cost of renting the video production equipment – all of which could not be avoided.

Therefore, to be more cost-effective, we estimated the shooting time to be only two weeks, so shooting locations and venues needed to be in Jakarta and the surrounding areas where the video participants and crew resided.

Based on an estimation of two weeks for production, the crew assessed that it needed an additional five members, bringing the total student crew to seven. The crew explained that these numbers were required to make the video within the two-week timeline. The crew members comprised one technical producer; one technical director; one script-writer; two cameramen; one sound-man; and one editor. The job of a technical producer is to manage the main tasks of the production process, starting from preparation to editing by making sure that the crew works according to their job description and according to the estimated schedule. The scriptwriter was in charge of converting an idea or concept into a more operational form, namely the script for the video. The technical director directed the video participants, and the cameramen and soundman shot the video according to the script. Two cameramen operated the video camera to document the various angle shots needed according to the director's direction and script. The soundperson's duty was to operate the sound recording equipment to record the dialogue of the video participants. An editor was in charge of collating and incorporating all shots and sounds taken so that there was consistency with the script and the objective of the video. From this explanation, I understood that the two crew members who were introduced by the Dean and who teamed up from the beginning took the roles as editor and camera person. The other five people joined the team after the decision on the budget, working time and the number of crew members had been agreed upon.

After negotiations, it was decided that all three stages of video production would be conducted in eight weeks. There would be two weeks for pre-production; two weeks for production, and four weeks for post-production. The agreed timeline was based on the crew's experience of video production and considerations of the limitations of this project's resources. Afterwards, we agreed on the final cost to conduct all three stages of production. The costs were covered by the funding available from my Curtin fieldwork allowance,

financial support and donations. I was successful in receiving financial support from the Post Graduate School of Social Welfare at the University of Indonesia, and donations from the Disability Studies Centre of the University of Indonesia. The Centre was supportive of my study and concerned with the video project, so they were willing to help with the budget shortage. The Centre required me to provide them with a copy of the video in return for funding.

b. Operationalisation of the CRG guidelines for the video production

The next aspect of the pre-production stage was the operationalisation of the CRG guidelines and the technical aspects of the preparation of the video production. I asked for the technical aspects to be documented in advance to be able to jointly scrutinise how the CRG guidelines were operationalised. The crew considered my request to be too demanding compared with their past collaborative experiences with other parties. I reminded them that this was not a commercial video project, but that this was a PhD PAR - where I have to document the process in detail. I also tried to engage the crew to adjust and respect each other due to the researcher being new to the video development process, while the crew was also just recently exposed to the area of disability and PAR. There were some difficulties related to time constraints, and therefore it was difficult to have routine discussions with the student crew as well as to get prompt responses to my requests because some of the student crew had prior engagements and traineeships due to the fact that it was the semester break. Thus, the crew and I faced challenges related to how to organise the details of the technical aspects. Therefore, we compromised by generating a schedule for the shoot – as presented in table 4.2 in the Chapter Four: research process – which also presented rough scenarios for the prospective video participants.

5.3.2.2. The production stage

The production stage was basically involved shooting or filming the video participants, and recording the various scenes and conversations. This PAR project was conducted in the natural world, and not in laboratory conditions where everything could be controlled to fit the intended outcome.

Consequently, I learned that to effectively execute the video shoot the crew and myself needed the flexibility to respond to at least three unexpected situations while still keeping to the schedule and the CRG guidelines.

Originally, the CRG and I planned for the participants to be filmed interacting naturally, but in reality, they were filmed separately due to the incompatibility of their schedules. The crew and I discussed the best way for this to work for the participants, and therefore we made several shooting schedules, as previously outlined in the research process section.

Initially, the CRG and I expected all video participants to be able to vocally express their scripted lines, but in reality, not everyone was able to do this during the time allocated, as they were not accustomed to acting in front of a camera. Whilst everyone was good humoured about it, a number of retakes were needed which extended the time taken. It was humorous, but also a bit frustrating for the video participants, crew and myself, when we had to retake the scene several times. Additionally, the weather was unfriendly for filming due to clouds or rain on some days, so that these unexpected conditions limited the variety and ability to record images as intended. In these instances, the crew and I could not always film retakes and we decided that when the expected messages had been expressed directly by one video participant, there was no need to wait until it was expressed by all video participants. Another unexpected situation was a classroom scene, where the teacher of the female student with a hearing disability was not present on the determined date. Instead, the scene was modified from the initial plan and I acted as her teacher and the production crew acted as her classmates.

Finally, despite some unexpected incidents, we accomplished the production stage as instructed in the CRG guidelines in Table 5.2. This was finished in ten days, which was the estimated duration of the filming schedule.

The video participants appeared to be pleased and grateful with the completion of the video shoot, as confirmed by the following expression, '*Alhamdulillah*

finally we can finish this shoot' (Dimas*², video participant with visual impairment). 'This was a great experience. Thanks (Mega*, video participant with hearing impairment)'. 'I really appreciated that I was included in this experience. I hope my contribution was meaningful despite my limitations during the shooting time (Adi*, video participant who was wheelchair user)'. 'Alhamdulillah' is an expression of gratitude in the Islamic religion, literally meaning 'praise belongs to Allah, the Lord of all the worlds'. This often becomes a spontaneous expression among Indonesian Muslims when they have or experience something to be grateful for.

5.3.2.3 Post production stage

This stage finalised the video, during which several edits and changes were made to the video. This stage is also called the editing stage.

This stage was the final and most challenging of the tripartite video development process, because the key objective of this stage was to capture the aspirations of Indonesians with disability who participated in this project; namely, (1) the CRG participants, (2) the video participants, and (3) the DPO member participants and the undergraduate student participants. They participated with varying intensity during the video-making process.

Accordingly, this study had three cycles of editing where edits and changes were made based on the opinions, aspirations and feedback from the participants of this study. Accommodating their aspirations and feedback was imperative for the video to be considered a disability awareness video for the Indonesian context. The editing process is summarised in Table 5.2.

^(*) The names of the video participants have been included here because, in the video, they were also introduced by name. They were not participants who asked for their identity to remain confidential.

Table 5.2. Video editing process in this PAR study

Process	Result	Basis of editing
1 st editing	1 st version DVD : 16 minutes and 18 seconds	Researcher instruction based on the CRG's guidelines
2 nd editing	2 nd version DVD: 12 minutes and 43 seconds	Based on the CRG participants' feedback on the 1 st version DVD
3 rd editing	3 rd version DVD: 13 minutes	Based on the DPO and undergraduate student participants' feedback on the 2 nd version DVD

The third version of the DVD was in Indonesian as it was intended as a prototype. Yet for the purpose of this thesis the video needed to be embedded with English subtitles. Due to a lack of time and budget, the process of embedding could not be done concurrently with the third edit that ended on August 29, 2011 (see the description of the action stage of cycle three in the chapter on research processes). Therefore, in addition to these three cycles of editing, there was a finalising process where the video was embedded with English subtitles in Perth in 2012, when I finally received the assistance of a native undergraduate student who majored in media and offered a low-cost fee.

The following sub section is a full description of the post-production stage.

a. The first editing

This initial editing stage occurred when the technical crew worked to compile all the audio visual data gathered during the shooting/filming (production stage). They worked in consultation with me and my instructions based on the CRG's guidelines for making the disability awareness video.

The first editing mainly involved compiling and transferring the audio visual data from the shooting. The data format was transferred from the camera cassette to a digital file for editing, then to a DVD user-friendly format. The editing covered technical aspects of the video, like its duration, the sound quality, and the subtitles so that the video would also be accessible for people with hearing disabilities.

b. The second editing - Feedback from the CRG participants

The second editing stage occurred when the CRG participants provided detailed feedback on the video being developed. Their feedback reflected their analytical and factual arguments based on their experiential knowledge of disability discourse and disability awareness. Their feedback included the five key issues outlined below, along with the amendments made.

- (i) Scenes have to serve a purpose and meaning which support the video's intention to raise positive disability awareness through positive images of people with disabilities and their lived experiences.

The CRG participants expressed dissatisfaction when they found that there were scenes preceding the video that seemed to be superfluous. This dissatisfaction was indicated by statements such as: "Remove the scenes in the first 24 seconds of display because they are not meaningful for a disability awareness video [sic.]" (CRG 6).

- (ii) The sequence of the pictures/scenes of the video had to be rearranged based on issues not related to the video participants.

The CRG participants wanted the video to focus on the main issue, and not merely focus on the life stories of the actor. This was described by comments such as: 'it was boring to watch such scenes which were arranged by person and not by issue' (CRG 7). And, 'the scene seemed to not be attractive or interactive because it was mostly shot in the oration positions. We don't need to make a video with sophisticated equipment, if it only shoots such scenes' (CRG 3)

- (iii) The pictures/scenes needed to correspond with the issues being presented by the actors, and they needed to be shown in a more active and focused way.

The CRG participants did not want disability to be depicted in a passive manner, but rather in an active and focused way. The majority of them found that the 'pictures and scenes did not correspond with the issues or description

being presented by the actors because they were mostly shooting passive scenes, namely talking while sitting' (CRG 10). Another participant stated: 'it was a pity to watch the actors in a sitting position while actually delivering meaningful descriptions; for example, about sloping ramps' (CRG 6)

- (iv) The CRG participants were critical of the music soundtrack and suggested that it was not uplifting enough to support the positive images and messages.

The CRG participants were dissatisfied when they found the music soundtrack to be melancholic and not fitting the spirit of the disability awareness video. The majority of participants agreed that '*the background music would be better changed so as not to sound melancholic and raise associations which connote weakness*' (CRG 5, and CRG 10).

- (v) PWD who were actors in this video should be central figures and directly voice positive messages of living with disabilities.

The CRG participants wanted the video participants to be able to vocally express the core message of positive disability awareness. This was the original expectation of the CRG participants and was set out in the guidelines. However, the video participants were not always able directly expressing the messages as the CRG's expectation.

Moreover, due to limited time and budget, we were not able to conduct any new shooting for new scenes as to respond to the CRG's feedback. To solve this gap, the CRG member offered to use narrator: '*The narrator's voice is important to assist this video in articulating the message intended and in raising awareness of disabilities in Indonesian society*' (CRG 5)

Therefore, the following headings outline the amendments to the video in response to these five key issues.

- (i) **Remove scenes from the video**

All of the CRG participants expressed dissatisfaction with the scenes in the first 24 seconds of the video. They insisted that the scenes did not serve a purpose with regard to the video's intention and messages. In contrast, the

student crew thought that such scenes were needed to set the context. Figure 5.2 gives an example of the scenes considered irrelevant by the CRG participants and need to be removed.

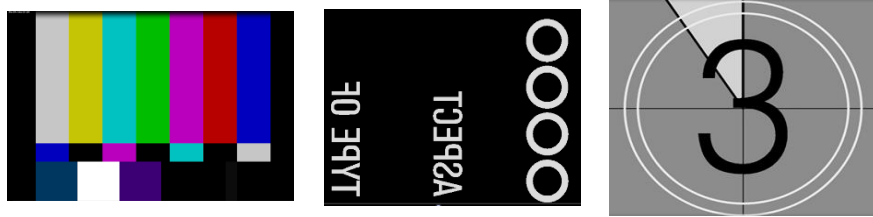


Figure 5.2. An example of the first 24 seconds of scene to be removed.

Removing these unnecessary scenes addressed the issue of the duration and arrangement of the video. Consequently, it open better opportunity to convey the three core messages of the disability awareness video.

(ii) **Rearrange the sequence of the pictures and scenes**

The CRG confirmed that the sequence of the pictures and scenes of the video needed to be rearranged based on issues and not on the video participants. This study found that a rearrangement of the sequence of the pictures and scenes as suggested by the CRG participants made the visualisation of the video much clearer and effectively improved the duration of the video. Figure 5.3 shows an example of the scenes relating to this feedback.



Figure 5.3 Video participants shot in speech/oration positions

(iii) **Substitute scenes with more suitable images**

As per the CRG's previous suggestions about rearranging pictures and scenes, they also suggested substituting monotone or passive scenes with more suitable images. New images supported the video participants' active expression of meaningful examples. Figure 5.4 shows an example of the original and altered scenes relating to this feedback.



Figure 5.4 Original and substitute scene that fit with the video participant's descriptions.

***Note:** In the clip subtitles above, “slopping” should be written as “sloping”. This was a human error during the embedding process with English subtitles due to a lack of resources for proofreading during the post production of video .

(iv) **Change the background music**

Discussions with the CRG participants about the musical soundtrack revealed that it seemed to indicate the stereotype that disability is closely related to sorrow, weakness, and pity. We then replaced the background with more positive and cheerful music to change the tone.

(v) **Add the narrator's voice**

The CRG participants suggested that a narrator's voice should be added due to the fact that not all video participants were vocally able to express the core message as expected by the CRG participants. Moreover, the limited time and budget prevented us from recording new video participants to refine certain scenes in the video. Table 5.3 shows examples of the script spoken by the narrator.

Table 5.3. Examples of the text message spoken by the Narrator

Text	Note	Time of scene
We are all the same, even though our appearance, our accent or the way we do things might be a little bit different.	Narrator's voice in Indonesian language conveying the text, which was intended as an affirmative message	00:05 – 00:18
Inaccessible public transportation leads us to find alternate ways for transport; that is, to modify motorcycles as three-wheeled vehicles.	Narrator's voice in Indonesian language conveying the text, which is regarded as an informativemessage that illustrates Adi's lived experience as a video participant who is a wheelchair user.	03:18 - 03:25
It would help people with hearing disability if the public transportation facilities were equipped with written signals that are easily read and recognised.	Narrator's voice in Indonesian language conveying the text, which is regarded as an informativemessage that illustrates Mega's lived experience as a video participant with hearing impairment.	03:26 - 03:35

c. The third editing - video showing sessions

As explained in the research process chapter, to enrich the data during the editing stage, the CRG participants and I arranged the video showing sessions to seek responses from the DPO member participants and undergraduate student participants.

They were asked to give their opinions and feedback after watching the awareness disability video entitled "Saya sama seperti anda, Anda berbeda seperti saya" ("I am the same - just like you; you are different –just like me") by filling out the feedback form. Both participant groups used the same form/instrument. This form asked for their opinions about ten issues and they answered with "agree" and 'do not agree". I then calculated how many of the participants answered "agree" and presented them in tables.

The 10 issues covered in the feedback form were as follows:

1. This video showed that the existence of PWD is accepted as part of natural differences in life.
2. This video showed the needs of PWD in everyday life.
3. This video showed the barriers experienced by PWD in everyday life.
4. This video showed the capabilities and human rights of PWD.
5. This video showed the contributions of PWD
6. This video explained that disability is part of diversity.
7. This video disclosed that disability issues and PWD were complex.
8. This video enabled the audience to understand disability and PWD better.
9. This video enabled the audience to have positive and appropriate attitudes to PWD.
10. This video enabled the audience to be open and accommodative to the needs and rights of PWD.

c.1. Feedback from DPO's member participants

There were 30 participants who were members of Indonesian DPOs, and the recruitment process for these participants has been explained in the research methods chapter. These participants comprised 10 people with visual impairment, 10 people with hearing impairment and 10 wheelchair users. The majority were studying in undergraduate programmes at universities in Jakarta, and the rest were a mix of people who had graduated from high schools, undergraduate programmes, and postgraduate programmes.

In general, the DPO member participants showed great enthusiasm in participating in the video session. In the introduction session, before watching the video, they made this comment: "in general, in most of our daily experiences – whatever the type of our impairment – we should fight harder to adjust to the environment due to social and physical barriers". Another group added: "especially, for us who are wheelchair users, unfriendly pedestrian paths, buildings, and public transport are everywhere around us. It's very hard to take part in daily life".

They concluded that people in the community can be grouped into three categories: “first, those who care and give help to Indonesians with disabilities; second, those who hesitate to interact or help; and third, those who do not yet care.” The video, of course, was aimed at the broadest level of the general public, encompassing these three categories. Table 5.4 shows that 30 DPO members had positive opinions on the 10 points of feedback assigned after watching the video.

Table 5.4 Feedback of 30 DPOs member participants

The video feedback components	DPOs participants' responses (n=30)
1. This video showed that the existence of PWDs is accepted as part of natural differences in life.	16 people agree
2. This video showed the needs of PWDs in everyday life	17 people agree
3. This video showed the barriers experienced by PWDs in everyday life.	16 people agree
4. This video showed the capabilities and human rights of PWDs	20 people agree
5. This video showed the contributions of PWDs	20 people agree
6. This video explained that disability is part of diversity	21 people agree
7. This video disclosed that disability issues and PWDs are complex	20 people agree
8. This video enabled the audience to have understanding about disability and PWDs	24 people agree
9. This video enabled the audience to have a positive and appropriate attitude toward PWDs	25 people agree
10. This video enabled the audience to be open and accommodative to the needs and rights of PWDs	20 people agree

Table 5 4 shows that the highest number is 25 people responding to the question of whether or not the video allows the audience to have a positive and appropriate attitudes toward PWDs. This feedback appears to connect with responses by some of the participants who voluntarily joined the discussion after the video session and stated:

“In my opinion, this video is good because it successfully delivers a very crucial message, which is how to adopt positive attitudes towards people

with disability. It is clearly delivered through visualisations that show, for example, how to guide a person with visual impairment, communicate with a person with hearing impairment, etc. (DPO 3)

Another DPO participant confirmed that “the actors and the message – through visualisations, sounds or text in the video - strongly conveyed messages which can generate positive attitudes toward PWD” (DPO 1).

Furthermore, the participants expressed that:

“The ending of the video strengthens the message because it clearly informed the audience about the universal ethic of a positive attitude toward people with any disabilities, such as:

- Asking the awareness of people whether they need any help. If he/she says yes.
- Questioning further about how to help him/her so that he/she can show or teach them.” (DPO 2)

This message is defined by the CRG participants as an affirmative message.

The majority of participants thought that short messages at the end of the video were effective and efficient ways to combat the inappropriate attitudes and behaviours of society toward PWD in Indonesia. Two DPO participants explained how these attitudes and behaviours are due to two deeply-rooted myths.

- **Myth: Dependency**

“this short but effective message could avoid contra-productive help toward PWD due to myths that all people with disability must be helped. For example, when they meet wheelchair users, usually they kindly push the wheelchair in their own way, and NOT in the way needed or approved by the person who uses the wheelchair due to their impairment” (DPO 3).

“This message was great to prevent the risk of making mistakes when people assume to help by grabbing a person with visual impairment,

without the helper telling or asking first, the person with visual impaired spontaneously may slap, or scream, or have any shocked reaction [sic.] (DPO 2).

- **Myth: personal tragedy**

“The message could keep us from common confusion about how to interact with and/or helping PWD. While the common assumption that helping a person with disability is troublesome...not knowing how to interact or help but hesitating to ask”. (DPO 1).

There was general agreement among the DPO member participants that the video was good enough in its substance, as indicated by one participant's comment: “[The] direct statement from the actors is strengthened with the visualisation and affirmative messages delivered by a narrator. It is very complete” (DPO 2).

However, the proportion of responses to some questions, such as ‘the video shows that the existence of PWD is accepted as part of natural differences in life’ (16 out of 30 agreed) and ‘the video shows the barriers experienced by PWDs in everyday life’ (16 out of 30 agreed) are worth noting. These comments indicated that the DPO member participants thought that the visualisation did not adequately convey a message of acceptance toward PWD and the barriers experienced by PWD. These comments also indicate that the video merely visualised a small part of the reality of PWD's daily life, which do not directly show the reality of a society that does not fully accept their existence.

Regarding the barriers, the PWD as DPO members are the most knowledgeable as they live with disability. They were concerned about the visualisation of barriers in the video, and they considered the video's visualisation of barriers to be too minimal. This feedback implies that the video should visualise more barriers, and what this means for PWD and how the audience could help to prevent or remove these barriers.

Another feedback from the DPO participants basically seemed related to merely technical aspect of the visualisation on the video. However, these feedback. Their feedback include such as follows:

1. 'Changing some pictures with pictures of a clearer colour and a variety of activities of people with disabilities' (DPO 1).
2. 'Revising the colour of the text from yellow to white or another colour that is eye catching and easy to read for any audience' (DPO 3).

Figure 5.5 below represents an examples of the feedback from the DPO members' participants. The first picture (before feedback) is the image of PWD activities, which mostly describes sporting activities. For this image, the participants suggested having a greater variety of PWD activities. Regarding the colour, it can be seen that the colour of the first image is similar to the text colour, so it is not eye-catching for the audience to read the message. In the second image (after feedback), the picture presents a wider variety of impairments and activities, namely a person with visual impairment working at an office, a person with a hearing impairment singing, a child with a physical disability, a person using sign language, and a person with a visual impairment boxing. As suggested by the participants, the text colour has been changed to white (see the whole video in the attachment; also the full text content of the video in the appendix; and its general description in the next section, 5.3.3, in this chapter).

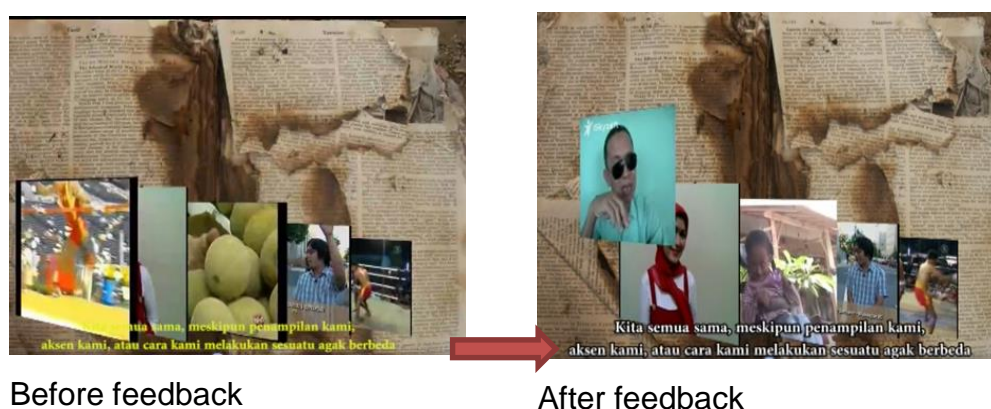


Figure 5.5 An example of revisions based on the DPO participants' feedback

3. *“Changing the background colour which is distracting because it is too dark”* (DPO 2). Figure 5.6 below shows an example of the scene related to this feedback, which accidentally occurred due to a technical problem during the second video editing process.

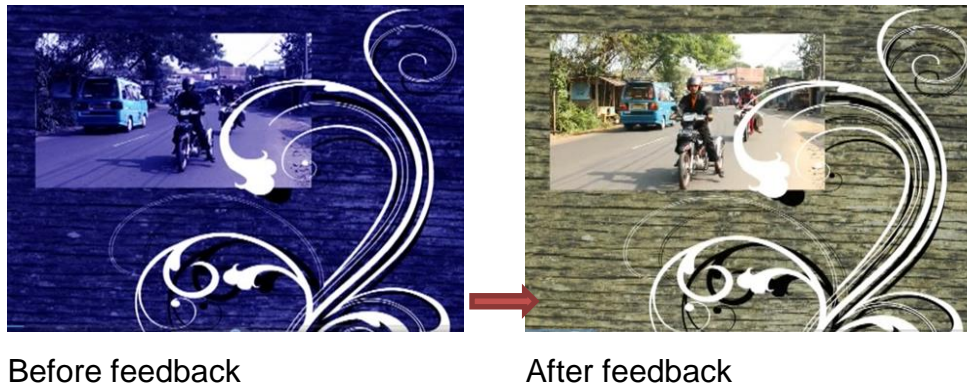


Figure 5.6 An examples of technical revisions from the DPO participants' feedback

The scene presents a video participants who have a physical disability and cannot use public transportation due to it is inaccessible. Therefore, to solve the problem of mobility, he rides a modified three-wheel motorcycle. It can be seen that, in the first image of figure 5.6, the background colour is too dark so that the audience would hard to understand what the scene is about. The feedback from the participants is respected and accommodated. After revision on the third video editing, the scene is much clearer.

Basically, Figures 5.5 and 5.6 are presented as an example of modifications following feedback from the DPO members.

At the end of the video session, the DPO member participants appeared to be pleased with and grateful for the video session, as indicated by the following three comments: *“O Alhamdulillah³, we can complete this video session well, and even receive reimbursement for transportation and lunch. Thank you very much”* (DPO 1). Further, *“wow, what a wonderful surprise, we get the koala key holder souvenir from Perth”* (DPO 2), *“well, we are all so lucky to be able to join this event. Hope our contributions to this session are worth [sic.]”* (DPO 3).

³ *Alhamdulillah* means ‘Praise be to God’.

The DPO member participants' comments at the end of the video session are relevant to this sub-section. These comments reflected positive feedback on the study's effort to implement the main principles of qualitative ethics, especially: respect for persons and beneficence (as described in Chapter Three, in the section on ethical approval and ethical issues). This principle emphasises doing no harm and doing good for participants. Their positive comments revealed that our efforts as PAR researchers worked. A similar practice of this ethical principle has been done by Valade (2004) in her PhD research in the US, which also showed that it worked for her participants.

Finally, the DPO participants expressed optimism in their feedback. This was indicated by the following statement: *'Dissemination of information by such a positive disability awareness video should happen on a regular basis, and be supported by interactive discussions where people with disabilities lead the process. All these can create a welcoming community to disability and to Indonesians with disabilities'* (DPO 1).

c.2. Feedback from undergraduate student participants

In total, 50 undergraduate students participated in this research project (see the chapter on research methods). Thirty students were from various undergraduate programmes at a private university in Jakarta, and twenty students were from various undergraduate programmes at a state university in Jakarta. As has been described in the earlier section - research process: observation stage of cycle three - the sessions with the undergraduate students at both universities and with the participants from DPOs used the same set of questions.

In general, participants showed great enthusiasm in participating in the video sessions, although it was college holidays and Ramadan, the holy Islamic month where the majority of participants were fasting throughout the day. This was indicated by their comments such as: 'It is a great event in this semester break' (UGS 1). 'I was honoured to join this interesting event and I am eager

to contribute to the process of developing a positive disability awareness video' (UGS 3). 'I was excited about this event. I'll do my best' (UGS 2).

The 50 undergraduate students gave positive opinions about the 10 points of feedback assigned after watching the video - as shown in Table 5.5.

Table 5.5 Feedback from 50 Student Participants

The video feedback components	Student participants' responses (n= 50)
1. This video showed that the existence of PWDs is accepted as part of natural differences in life.	26 people agree
2. This video showed the needs of PWD in everyday life	43 people agree
3. This video showed the barriers experienced by PWD in everyday life.	42 people agree
4. This video showed the capabilities and human rights of PWD	31 people agree
5. This video showed the contributions of PWD	30 people agree
6. This video explained that disability is part of diversity	29 people agree
7. This video disclosed that disability issues and PWD are complex	30 people agree
8. This video enabled the audience to have an understanding of disability and PWD	25 people agree
9. This video enabled the audience to have positive and appropriate attitude towards PWD	36 people agree
10. This video enabled the audience to be open and accommodative to the needs and rights of PWD	32 people agree

Table 5.5 shows that the highest number is 43 people (86%) stating that the video confirms the needs of PWD in daily life. This seems to be related to the following comment:

This video, in my opinion, was good in visualising the needs of people with disabilities to be perceived as human beings who are more alike than different from other people. For example, despite their limitations due to their impairment, they can interact and communicate with other people. One of the things that I mostly remember from this video was the visualisation of the female with a hearing impairment who communicated

with her friends and vendor in the canteen without sign language. Previously, I thought it would be difficult to interact and communicate with people with hearing impairment if we don't understand sign-language (USG 1).

Another participant commented that:

This video is good because it delivers clearly the needs of Indonesian people with disabilities in daily life such as transportation for mobility, communication, and education” (USG 2)... even the needs for doing prayers, are also shown in the video. These needs are ignored because they are not utilised by non-disabled people” (USG 4).

When confronted with the lowest number of responses, which was 25 (50%, question 8: This video enabled the audience to have an **understanding of disability and PWD**), critical issues were raised. In their opinion, the video had not allowed the audience to understand disability and PWD properly. They explained that: ‘the video only presents three PWD so it may be difficult to expect that it could allow the audience to understand comprehensively PWD (UGS 6)’. Another participant said, ‘it would be better if the video did not only portray three kinds of disabilities, such as visual impairment, hearing impairment and physical impairment, because disability is related to so many kinds of impairments’ (UGS 5). This clearly indicates that the undergraduate student participants have the opinion that a proper understanding of PWD is related to the variety of people with disabilities presented in the video. However, another participant responded quite emphatically that:

“This video indeed has some weaknesses, such as the lack of varied PWD actors and detailed information of every kind of disability. But, the weaknesses, in my opinion, can be compensated by the existing visualisations and messages. The most important thing is the short meaningful message at the end of video, saying *that the way of helping people with disabilities is simple*. In my opinion, it could also be interpreted as: the simple way to understand a person with disability is “you only have to ' ask directly but respectfully'.” This is a very effective

and efficient message since it can be applied to all. By asking directly, we can learn from the main source and we avoid the idea that people with disabilities are incompetent, incapable, and that interacting with a disabled person is troublesome. Therefore, the simple general message can increase positive awareness towards people with disabilities” (USG 3).

Because the session with the students was conducted using the same video and process as those used with the DPO member participants, there was no new additional feedback of substance from these undergraduate student participants. However, they reminded that the video will be better if it could be accessible.

They also expressed their optimism for, and positive feedback on the video. They argued that the video, ‘I am the same - just like you; you are different - just like me’, was good enough to be a preliminary model of disability awareness video for the Indonesian context.

To present a clearer and comprehensive description of the findings related to the third objective of this study, the following section provides an illustration of the video to briefly describe the disability awareness video developed in this PAR.

In order for readers to fully understand the video being develop in this study, a copy of the video is attached to this thesis in DVD format. It is 13 minutes in duration and contains the MOV file of 2.9 Giga Bytes (GB). It can be played in a computer or a DVD player. The file of this video is also intended as an evidence of the collaborative work conducted between me and the Indonesian PWD, who were the research participants and co-researchers in this PhD PAR. Also, it is evidence that they were equal, valued, capable, experts, and a vital source of knowledge in this ‘**p**articipatory’ ‘**a**ction’ ‘**r**esearch’.

A full text content of the video, along with the video sequence and the supporting pictures taken from the content of the video is attached in Appendix D. The full text description is intended to complement the following the section

5.3.3, which provide general illustration of the disability awareness video developed in this study. In doing so, the video becomes accessible for persons with hearing impairments who are interested in finding out further what is screened audio-visually in this disability awareness video.

5.3.3 The Illustration of the Disability Awareness Video developed in this study.

The video was a key factor in this study and reflected the outcome of an important PAR study. It also is useful in providing a link between the PAR process and the challenges in producing something that is authentic in reflecting disability issues.

As described earlier, the video content was not produced in a straightforward way; it had been edited several times following feedback from the CRG and other participants. This section presents a general illustration of the final version of the video confirming that it was developed to meet the study objectives and expectations despite various limitations to the video production.

The video is in Indonesian with English subtitles for the purpose of this study. In Indonesian its title is '*Saya sama seperti Anda; Anda berbeda seperti saya*', and in English is called 'I am the same - just like you; you are different - just like me'. This video is a semi-documentary and a semi-PSA because the duration is 13 minutes, a common timeframe for a short documentary. However, it serves as a PSA that functions as educational material targeted at the public, especially people in campus communities. This video is intended to enable people to:

- have a good understanding of disability and people with disability;
- adopt a positive attitude toward people with disability; and,
- to act/ behave appropriately when engaging with people with disability.

The video contains three kinds of messages: informative, instructive/ educational messages, and affirmative messages.

It commences by showing the international symbol of people with visual disabilities, hearing disabilities and physical disabilities. It then shows pictures of several activities with a range of people with disabilities. This includes people with visual disabilities typing with a braille type-writer; a female with a hearing disability singing using sign language; children with physical disabilities eating; a female and male with hearing disabilities communicating; and a male with a visual impairment who is a boxer (as part of being involved in sport activity).

This video portrayed three Indonesians with disabilities who were the main actors. Two of them are undergraduate students - a male with a visual disability, and female with a hearing disability - and a third person, a wheelchair user who has already graduated from university. They performed their daily routines while articulating the rights of people with disabilities in Indonesia. Each participant in the video introduced herself/himself by giving their name, age, education and their disabilities. In sharing their thoughts and activities with the viewers, the participants in the video showed the situation they are in and the difficulties they encounter with mobility and transportation (for example, going to, moving around, and returning from campus). As suggested in the feedback from the CRG, a narrator's voice is heard in a few scenes to reinforce the message delivered by the video participants and their significant others.

The video participants also showed how they interact and communicate with others in campus life, such as in the library, cafeteria, mosque or house of prayer, group study rooms, and in the classroom. The participants describe their thoughts and activities in the video, supported with explanations or opinions from others, such as their families (i.e. parents, spouses and friends). For example, Adi, a participant in the video, as a wheelchair user explained that:

There are several etiquettes to help wheelchair users [sic.]. You cannot just push whenever you want. You need to ask them first whether they

need help or not, because maybe they can help themselves (Adi, minute 06:30-06:34).

I hope that people do not underestimate us just because we have disabilities. Nor judge us as incompetent because we all have differences. People need to understand that even people with disabilities have differences in the level of disability, education, and strength of each individual. The best way is not to see us as weak people (Adi, minute 10:23-10:38).

Adi's wife, Darsih, supported her husband by stating, 'he is actually quite independent. I have never spoiled him because he is disabled [has a physical impairment]. Most of the time, he does things on his own; he even helps me to do housework'.

The video shows the techniques and the general etiquette of helping people with disabilities. For example, 'a simple effort to help them is to ask whether they need help. If they say yes, then ask them what assistance they need and how we should help them' (Narrator's voice at 11:53).

The video ends with the participants' hopes and five affirmative messages that emphasise positive visualisations and messages about disability and people with disability to disspell deep-rooted myths held by the general public in Indonesia. It also reaffirms the need for the audience to be involved in, and contribute to a welcoming society.

This illustration has completed the description of the findings of this study as to the CRG participants' aspirations about the development of the disability awareness video for an Indonesian context.

Summary of chapter

In total, there were four groups of participants actively involved in this research project, which included 43 Indonesians with disabilities. This included the ten CRG participants, the three video participants, and 30 DPO members. The fourth group was 50 undergraduate students without disabilities.

The first section of this chapter on the research findings indicated that the realities of PWD's lives in Indonesia is discouraging. This is due to barriers which PWD face in their daily lives. These are rooted in inappropriate attitudes and behaviours of the majority of society, and lead to negative practices and policies, which result in social and physical inaccessibility, which prevent them from social inclusion. All participants agreed on the need to raise positive disability awareness. This is needed to overcome the existing negative public awareness about Indonesians with disabilities.

The second section of this chapter confirmed that current disability awareness is still negative due to people's mindsets, which are predominantly based on harmful myths and assumptions as revealed in the first section of this chapter. As a result of this finding, this study recorded the CRG member's ideas regarding what is needed to respond to the existing negative awareness of the Indonesian public about PWD.

The third section of this chapter provided detailed feedback on the CRG participants' advice and aspirations. It included the challenges, methods and processes of developing a disability awareness video for an Indonesian context. One of the most valuable contributions of these findings was the CRG suggestion of raising awareness of disability through a video made specifically for a broad Indonesian audience. The CRG guidelines for such a video covered several aspects – the target, type, media, format, duration, actors, purpose, theme and content. These detailed guidelines led to a smoother video-making process in quite pressurised circumstances. Within the guidelines, the purpose of the video – a very important aspect – was very clearly formulated.

The most crucial aspect of the CRG's video-making guidelines concerned the disability awareness video's content and the need for the video to include three

kinds of messages: an informative message – consisting of explanatory and instructional messages, an educational message, and an affirmative message. This meant that the video delivered knowledge that enables people to have a better understanding of disability and people with disability, diversity, their roles, rights and activities. Besides general knowledge, the video also educates its audience on how to communicate and interact with PWDs. Moreover, it conveys affirmative messages. Thus, the video has three elements: knowledge, skills, and attitudes/values to be internalised by non-disabled people. It is expected that, through this video, mainstreaming disabled people's issues and raising positive disability awareness will occur. The positive messages in the video strengthen the core message of positive disability awareness. This is crucial to encourage the audience to welcome PWD into society. In this sense, it promotes social responsibility for all members of society. As one participant mentioned, 'dissemination of information by positive awareness in the video on a regular basis, and supported by interactive discussion where people with disabilities lead the process, can create and welcome a new community for people with disabilities and Indonesians'.

CHAPTER SIX

DISCUSSION

This study is driven by the main research question: In what ways can awareness-raising strategies be used to increase the understanding of people with disabilities (PWD) as active members of the Indonesian society? This question is complemented by three key sub-questions: (1) What are the realities of an Indonesian PWD's life in Indonesia? (2) What is the state of current disability awareness in Indonesia? (3) What are the research participants' thoughts and ideas on the development of disability awareness-raising strategies in an Indonesian context?

The study was a collaboration with a purposive sample of Indonesian PWD to achieve the three study objectives. To describe and analyse the realities of PWD's life in Indonesia. To explore and analyze key issues related to the current disability awareness in Indonesia. The final objective was to develop a disability awareness-raising strategy proposed by the research participants.

This chapter presents a discussion of the study's results, which are presented in Chapter Five. The discussion is organised based on the three research objectives and then integrated with the literature.

6.1. The realities of PWD lives in Indonesia

The research participants in this study perceived that the reality of Indonesian PWD life in Indonesia is still upsetting due to the fact that discrimination is still experienced by the participants and most Indonesian PWD. Discrimination is derived from the negative behaviour and attitudes of the majority of society, who are still strongly influenced by myths. This is viewed as ironic when we consider the fact that the Indonesian Government has passed Law Number 19 (2011) concerning the legalisation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD)

because the CRPD ensures full and equal enjoyment of all human rights, including for citizens with disabilities.

This study confirms that the discrimination and social exclusion faced by Indonesian PWD are closely related to at least five realities. First, the majority of the Indonesian public has not accepted Indonesian PWD as a part of the diversity of everyday life due to the false belief that PWD are different, or not fully human beings. Second, the majority of the Indonesian public is still unaware that Indonesian PWD share common interests and needs with other members of society. Third, the majority of the Indonesian public is still uninformed that Indonesian PWD are entitled to inherent rights as citizens and that the public has the obligation and responsibility to provide opportunities for them to enjoy their rights. Fourth, the majority of the Indonesian public is still neglectful of the fact that Indonesian PWD have capabilities - despite their impairment - due to the false belief that they are incapable, inferior to others and a burden to their family and society. Fifth, there is still a strong belief that Indonesian PWD are passive, and incapable of contributing to their communities.

In the following section, five key issues are identified and discussed with regard to the realities of PWD lives in Indonesia. These five issues are: barriers, ableism, the model of disability, the model of disability in Indonesia and cultural issues, and PAR.

a. Barriers experienced by Indonesian PWD

The research findings reveal the discouraging reality that Indonesian PWD lives are closely connected to the negative attitudes and behaviour of society toward PWD. This is confirmed by, and consistent with a previous study that pointed out that: 'Society has made them unwelcomed in many activities and opportunities generally available to other people without disabilities' (Shapiro, 2000, p. 124). It is also consistent with previous reports that stated Indonesian PWD face discrimination and inequality, which are sparked by prejudice, stigma, marginalisation, ignorance, indifference and a lack of

concern from the government, employers, neighbours and schools (Byrne, 2002; Fuad, 2008a, 2008b; Komardjaja, 2001a, 2001b; Sirait, 2008).

Furthermore, these negative public attitudes and behaviours have been found to be significantly influenced by damaging myths. The findings of this study support Kirst-Ashman's claim (2010) that one of the critical issues around disability is myths, such as: 'the more severe a physical disability, the less intelligent the people; people with physical disabilities are unable to function normally in society; and people with one kind of disability also have other disabilities. The third myth is sometimes referred to as the spread of disability' (p. 301). This study identified at least four existing myths among Indonesian society: that disability is God's punishment for their ancestors' sins and disgrace; disability is a personal tragedy and misfortune; disability is a disease or sickness; and disability means dependency.

In the findings section, the discrimination, exclusion, rejection, and low expectations experienced by the participants are discussed to show the relationship among myths, attitudes and behaviours. According to disability studies literature (i.e. Barnes & Mercer, 2010, p. 30; Oliver, 1996, p. 33; Pfeiffer, 2005, pp. 31-34), these realities emerge as barriers encountered by the participants and other Indonesian PWD. There were at least three kinds of barriers, namely physical, attitudinal and systemic (Parnes *et al.*, 2009):

Physical barriers include inaccessible public buildings i.e. multi-storey schools without ramps or lifts, inaccessible public transportation i.e. public buses or trains without lifts for wheelchair users or any signals to help people with visual or hearing impairments. Attitudinal barriers consist of, among others, denial of the same values, rights, needs, and an underestimation of abilities of PWD. Systemic or institutional barriers that limit opportunities for PWD i.e. educational institutions that do not allow students with disability to attend or workplaces that reject individuals with disabilities (p. 1174).

There are other explanations in the UN CRPD (2007), which include:

Technological barriers ... [are those which] prevent people with hearing and visual impairments from communication; and social barriers, in the form of attitudes and practices, convey explicitly or implicitly that PWD are either unwelcome or are considered less capable than everyone else (p. iii).

Thus, it can be concluded that social barriers and attitudinal barriers, as they are defined above, are one and the same; while technological barriers are an extension of the physical barriers presented by Parnes. These barriers prevent many people with certain physical, mental or intellectual conditions from enjoying life in the same ways as other people in their societies.

Additionally, these attitudinal barriers may lead to discriminative regulations or policies as a product of government officers who are insensitive to the issues of disability and PWD. This is understandable, as the government officers or members of the apparatus have grown up in a society where the aforementioned negative myths, attitudes and behaviours are prevalent. Hence, the negative views of PWD have been internalised. As a result, Indonesian PWD often impose on the state changes which are difficult to expect without government officers or apparatus being sensitive to disability issues. Accordingly, this affects the persistence of discriminative regulations or policies.

Myths influence public negative perceptions of PWD, such as referring to the latter as 'others' and implying they are not equal or of the same value as the rest of society. According to most of the CRG participants' life stories, Indonesian PWD experience attitudinal barriers, such as the false belief that they are incapable of exercising, fulfilling and enjoying their needs and rights. These rights are, for example, the need and right for education; the need and right for work and employment, the need for love, affection and meaningful, intimate relationships, the need and right for mobility, and the need to engage in spiritual activities. These findings confirmed, and are consistent with a

previous study that explained that PWD are mostly viewed as being not equal to people without disabilities (Ollerton & Horsfall, 2013, p. 617), which leads to ableist assumptions and attitudes (Radermacher, 2006, p. 134), and unwelcome behaviours such as unfair treatment in employment and in the workplace (Cocks & Thoresen, 2013, p. 25), social exclusion and discrimination (Loja *et al.*, 2013, p. 200; Radermacher *et al.*, 2010, p. 333; Pfeiffer, 2005, p. 31). The majority of Indonesian society, including government apparatus and decision-makers, have these negative attitudes, which lead to insensitive and discriminative regulations.

b. PWD life in Indonesia and ableism

The study findings also confirm previous studies related to the existence of ableism or ableist attitudes and behaviour, conducted by Linton (2006), Radermacher (2006), and Loja *et al.* (2013). Showing ableism is alive and part of the lives of PWD in Indonesia as it is in other countries.

This study also revealed that the participants, as Indonesian PWD, experience the 'ableism' phenomenon, which discriminates and even prevents them from fully participating in their communities. Ableism helps to provide a context to understand the barriers PWD face in their daily lives. As described in Chapter Two, ableism is an ideological concept or term that refers to the social practices, designs and organisations that are constructed based on the perspectives of the able-bodied, or people without disabilities. Accordingly, these social practices, designs and organisations prevent PWD from fully participating in their communities and society. This results in 'society's failures to provide appropriate service and adequately ensure the needs of disabled people are fully taken into account in its social organisation' (Oliver, 1999, p. 32).

Ableism can also be identified in the realities of Indonesian PWD's daily lives: First, ableist attitudes exist in the form of people's low expectations of the capabilities of PWD, despite many Indonesian PWD - including the CRG

participants - having good capabilities, sometimes even better than people without disabilities.

Second, ableism is present in people's comments or use of language that degrades the ability and worth of PWD. An example is when people say 'are you blind?' to people with no visual impairment who are unable to find something within their field of vision, or when they accidentally bump into something which could easily be avoided in the first place. Or people also tend to make comments such as 'are you deaf?' to people without hearing impairment who do not respond to a call or instruction; or the expression 'are you an idiot?' to people without intellectual impairment who create unnecessary mistakes; or 'is he/she autistic?' to people without such an impairment who refuse to mingle or socialise with others. There are still many more examples of ableism in society. This study recognises that ableism is infused in language use as a social semiotic phenomenon, as will be discussed in more detail later in the next section.

Third, ableism exists in the form of people's expectations of the impairment itself, which present the greatest obstacles to the participation of PWD. This is the most common example of the ableist attitude that is still prevalent now as experienced by Indonesian PWD, including the CRG, as described in Chapter Five. For example, CRG 3 was discriminated against regarding educational opportunities, when her school expected that her visual impairment presented the greatest obstacle to her participation in mainstream school. PWD also face discrimination with regard to public transport accessibility. Such as CRG 7, who has a physical impairment, was expected to not be able to travel alone on public transport due to their disability.

The following illustration in Figure 6.1, adapted from Oliver (2012, p. 154), describes in a simplistic way the negative relationship between the needs and services experienced by PWD (Oliver preferred the term 'disabled people'; see Chapter One), which is closely linked to the 'ableism/disablism' concept.

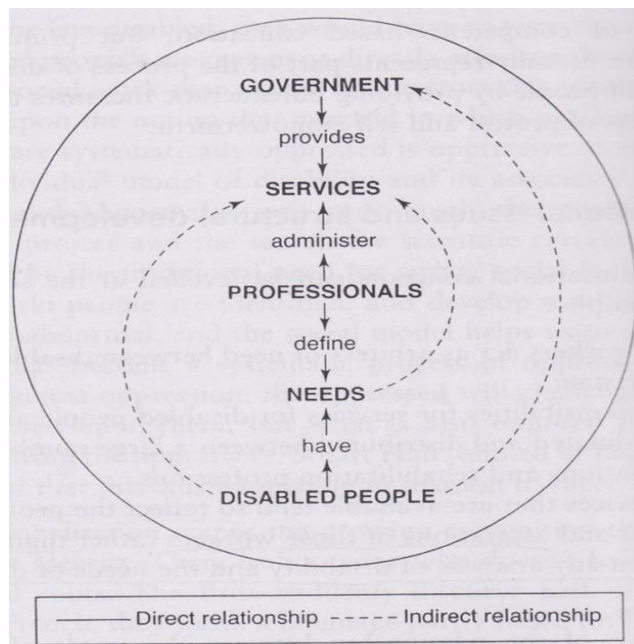


Figure 6.1. The relationship between needs and services (source: Oliver, Sapey & Thomas, 2012, p.154)

Figure 6.1 illustrates that the negative relationship between the needs and services experienced by PWD is due to the fact that the services available to them, mostly provided by the government, are based on needs as defined by able-bodied professionals. In other words, the service is defined by non-disabled standards. This means services are not usually based on the needs that are directly expressed and identified by the PWD themselves. Thus, they reflect ableist behaviour, and practices based on ableism discriminate against PWD.

These ableist practices are deemed a negative reality in contrast with general global agreement, as the United Nations has stated that 'PWD need to be included in development efforts, both as beneficiaries and in the design, implementation and monitoring of interventions' (WHO, 2011, pp. 12-13). The UN acknowledges PWD as experts on their lives, while in contrast, the reality shows the dominance of the Medical Model, where professionals are the experts on, and decision-makers in the lives of PWD.

Furthermore, Figure 6.1 reflects a strong link with social role valorisation (SRV), which confirms that Indonesian PWD have experienced discrimination

due to social devaluation (Wolfenberger, 1992), meaning that they are not as socially valued as other people without disabilities due to the negative images produced by myths. The findings confirm that participants often find it difficult to experience dignity, autonomy, respect, supportive relationships and participation in their society. In addition, the findings also show that they are devalued and considered to be dependent and submissive, while the non-disabled, especially professionals, are powerful and superior.

c. The model and understanding of disability in Indonesia

Finding that the reality of PWD lives in Indonesia is upsetting reflects the influence of the existing model of disability among the Indonesian general public. This is confirmed by the statement that models are ‘the source of our attitudes and behaviours’ (Shapiro, 2000, p. 88). Thus, the existing model of disability influences the way in which people think, perceive, interpret and approach or treat disability and PWD in Indonesia. A model of disability provides meaning and direction to interpret, understand and respond to disability and PWD.

Referring to disability models discussed in Chapter two, this study confirms that the dominant views and perspectives existing in Indonesian society are predominantly the Medical Model and Moral Model of disability. The Moral Model of disability is marked, among others, by a strong belief in the myth that perceives disability as God’s punishment for sinners. The Medical Model of disability perceives disability as a personal tragedy and sickness, while PWD are viewed as the victims of their impairment, who need to be ‘cured’ via professional medical intervention. These two models view PWD as not having the same value as average people; as ‘others’ and existing outside mainstream society.

These ways of viewing disability have been confronted by research participants in this study. The CRG members were able to effectively resist them with their achievements described in their profiles in Chapter Five.

The following Table 6.1 is intended as a simplified overview of these three major models of disability, as they have been employed to provide meaning and direction to the interpretation, understanding and response to disability.

Table 6.1. Interpretation of three models of disability

	Moral/Charity Model	Medical Model	Social Model
Impairment is:	Natural phenomenon Disfavour differences; disgrace	Biomedical – anomaly phenomenon Health-related inability	Social phenomenon Human experience
Disability perceived as:	God's punishment for sins or wrongdoing	Personal Tragedy	<ul style="list-style-type: none"> • Restricted/loss opportunity • Social oppression • Human Rights violation
Disability caused by:	Disadvantage, misfortune, sins	Deficiency and 'abnormality' in the individuals	Barriers that arise from social practices & structures
Disability viewed in:	Dichotomy: <ul style="list-style-type: none"> • good vs bad • favour vs disfavour 	Dichotomy: Sick vs well ability vs inability	Continuum: disability - ability
Locus of problems	The Individuals (private problems)	The individuals (individual problems)	The society (societal problems)
Response/ Focus of attention	Exemption, Reliefs, Donation	<ul style="list-style-type: none"> • Individual adaptations • Diagnosis by professional • Cure via medical treatment & rehabilitation services 	<ul style="list-style-type: none"> • Removal barriers to participation & inclusion • Social change
Control lies within:	Religious groups, Charity organisations	Medical professionals	PWD
Implication	Dependency Segregation, Stigmatisation	Stigmatisation, Disempower, Discrimination	Equal opportunity, Empowerment
PWD viewed and treat as:	Beneficiary , Unequal/inferior, Dependent Needy	Sick role, Dependent, Incapable, Unequal	Victims of uncaring/ignorant society Citizens with equal rights & responsibilities
Attitude towards PWDs	Fear, anxiety, pity	Fear, Prejudice & Stereotyping, Distancing/excluding	Respect ; Equal
Behaviour towards PWDs	Patronisation; Segregating	Discrimination, Inequality, Distancing/excluding/ segregation	Integration/Inclusion Reasonable accommodation

Compiled from multiple sources, i.e.: Cocks & Allen, 1996; Cocks & Duffy, 1993; Roongtim, 2010; Rothman, 2003; Smart & Smart, 2002

The two dominant models lead to 'labelling' PWD which has negative connotation and powerful negative effect such as stereotyping, discrimination, and prejudice (Rothman, 2003, p. 8).

In contrast, the Social Model of disability focuses on promoting equal rights, equal opportunities, as well as eliminating or removing barriers for social inclusion of PWD. This includes changing barriers in the form of negative disability awareness into positive disability awareness, which is characterised by acceptance in at least five components, as illustrated in Figure 6.2. This figure is intended as a simplified illustration of the current disability awareness situation in Indonesia, according to CRG participants and other participants of this study.

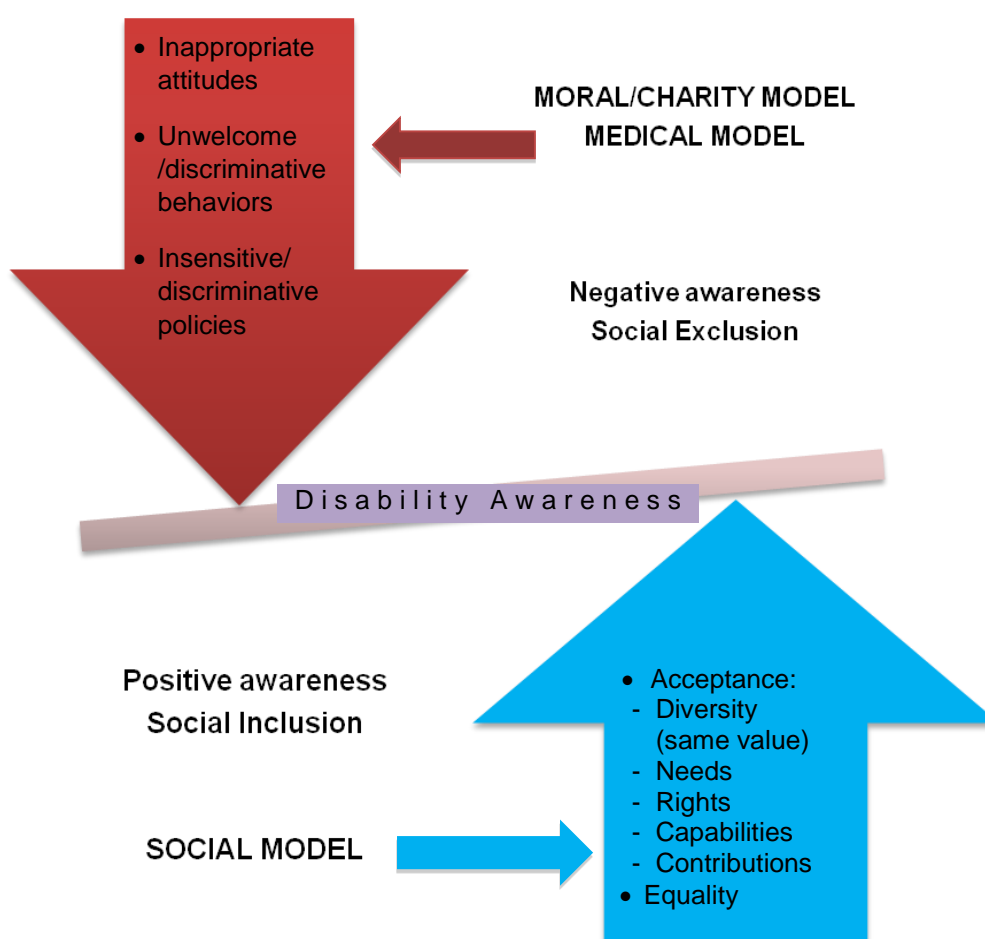


Figure 6.2 The relationship between the current negative reality of disability awareness in Indonesia and existing models of disability

d. Model of disability in Indonesia and cultural issues

This study confirms that the Moral Model, the Medical Model and the Social Model of disability currently co-exist and are being used concurrently in Indonesia. However, the first two models are more dominant, as the Moral Model is based on religion doctrines while the Medical Model is supported by professionals and laws. Indonesian activists with disabilities and their advocates or supporters, on the other hand, support the Social Model of disability.

This is consistent with the explanation in the literature that the Medical Model and Moral Model are still dominant in England and the USA, even though the Social Model of disability originated there and both are considered to be developed countries.

Furthermore, this research recognises that the existence of the Moral and Medical Models in Indonesia is a result of colonialism, which lasted in Indonesia for more than three centuries as described in Chapter Two. It can be inferred that the colonialists perceived PWD as not fitting with many of Western societies' values of having physical strength, adroitness (Rothman, 2003, p. 17), a beautiful figure and being physically attractive (Zastrow, 2004, p. 546). As a result, PWD were often kept apart from others in a form of social isolation, and judged and treated based on the Charity and Medical Models. Due to their impairments, Indonesian PWD were assumed to be unproductive, so they needed to be 'normalised' through nursing houses or rehabilitation institutions, which were first built by the Dutch army around 1621. After the liberation war and Indonesia's independence in 1945, these nursing homes and medical centres built by the Dutch colonial government were taken over by the Indonesian government and used to rehabilitate the Indonesian military forces who became disabled because of war (Yulianto, 2011, p. 13; Thohari, 2013, p. 59). However, there were no official data regarding how many Indonesians PWD were living in the various forms of institutions during the colonial era of the Dutch in Indonesia, and after the Indonesia independence.

Before the colonial era, according to an Indonesian historian, Indonesian people, mainly those living in Java, lived in harmony and with respect (Nugroho, 2012). People who had differences due to impairments were perceived as humans and treated with respect as average people; thus, the sentiments toward PWD were not negative. Indonesian culture, especially Javanese culture, appreciated the importance of living in harmony. This is further evidenced by stories of traditional puppets. In these stories, the characters are very diverse, and characters such as *Semar* and *Petruk*, who are physically disabled, and *Destarata*, who is visually impaired, are all treated respectfully and not stigmatised. They are even considered to have some sort of divine power (Carey, 2013). Javanese society views wayang characters with impairments as figures who are admired and respected (Thohari, 2013).

Furthermore, prior to colonisation, Indonesian culture was characterised by the rule that everybody had to unconditionally respect each other, including PWD. This was in contrast with how Western colonialism judged and treated PWD based on the Moral and Medical Models, which are linked to unfavourable behaviours, such as not respecting people who have different appearances, and considering them not to be of equal value as the rest of society.

Finally, this research concludes that the ‘original’ Indonesian culture – meaning that which existed before colonial influence – was already consistent and in harmony with the Social Model of disability. As previously mentioned, the development of this model was driven by British disability activism around the 1970s to challenge the historical oppression and exclusion of, and discrimination against PWD in Britain. Thus, the models of disability co-exist in Indonesia: the Moral Model and the Medical Model of disability, which were introduced by colonialists and perpetuated by the influence of the colonisation of Indonesia’s contemporary culture, education system, law and architecture; and the opposing Social Model of disability that is well-suited to the ‘original’ Indonesian culture. Indeed, the Social Model of

disability did not represent a new or different model of disability in that it had an identical spirit to the original Indonesian culture.

e. The social model of disability and PAR

The two fundamental approaches in this study are the Social Model of disability and the methodology of PAR, which are closely related to each other.

Equal rights and opportunities are a central issue in the Social Model of disability, which claims that people with disabilities have the same rights as all citizens without disabilities. The emergence of the Social Model of disability is closely related to the demand from the disabled rights movement to shift the research agenda. The shift includes three important elements: first, the active role of PWD in research and not only as research objects, as happened in traditional research; second, the acknowledgement that PWD's lived experiences are a source of knowledge; and third, a renewed research focus on investigating and removing the barriers and limitations placed on PWD by an inaccessible world (Oliver, 1992; Barnes, 1993, 2003).

PAR is considered the most compatible research approach with the Social Model of disability because PAR emphasises that people with lived experiences of disabilities are experts and a vital source of knowledge. PAR respects research participants as capable agents, putting them in the position of equally important stakeholders during the research process, and emphasises collaboration and dialogue among the stakeholders of the research (Kemmis & Taggart, 2008, p. 272; Kindon, Pain, & Kesby, 2010, p. 14). Thus, PAR is considered to be well-suited to addressing the Social Model of disability. It is consistent with the method's definition as 'a research approach involving researchers and research participants to work collaboratively to achieve a shared understanding of issues and problems and bring about change for unsatisfactory conditions' (Wadsworth, 1993, p. 1), which 'affirms people's rights and ability to have a say in decisions which affect them' (Reason & Bradbury, 2006, p. 10).

PAR was employed as the principal method in this study for four reasons. First, by defining all participants as significant stakeholders during the research process, this study intended to implement equality, which is highly respected in the Social Model of disability. This designation allowed the participants to articulate their knowledge and aspirations, along with their enthusiasm and commitment to the research.

Second, this study considered research participants as capable agents and gave active roles to all participants. This legitimatised their concerns and feedback, which clearly reflected their perspective on the Social Model of disability and guided the disability awareness video production in this study. Subsequently, employing PAR also enabled me - a novice participatory action researcher - to gain valuable direct experience in working with people, and not on or for them (Sayers, 2006).

Third, emphasising collaboration and dialogue with the participants enabled a reduction of the hegemony of the researcher as the expert and the PWD as the objects of the research. Moreover, this also provided a win-win solution with regard to unexpected difficulties during the research process.

Four, the participants' experiences as Indonesians PWD proved to be a valuable source of knowledge in understanding the inadequacies of existing disability awareness in Indonesia.

These reasons were consistent with previous studies, which asserted that, firstly, PAR acknowledges that marginalised groups have specific knowledge of their own lives, which needs to be valued (Hergenrather & Rhodes, 2002, p. 60; Ishak, 2013, p. 125). It tries to reduce the distance between the researcher and the 'research subjects' (Katsui & Koistinen, 2008, p. 1). Second, PAR enables participants to work as a collective, sharing objective and subjective aspects of lived experiences, thus eliciting and analysing the popular or common knowledge people possess, as complemented by the researcher's views (Selener, 1997, p. 20).

6.2. Key issues about current disability awareness in Indonesia

This study's participants reveal that the current disability awareness in Indonesia is still negative. This closely related to negative realities faced by Indonesian PWD as have been previously described and discussed. In the following section, three key issues about disability awareness in Indonesia are discussed: the lack of definition or concept regarding disability awareness, insufficiency of existing disability awareness-raising strategies, and the lack of availability of disability awareness videos in Indonesia.

a. Conceptualisation of disability awareness and disability awareness raising

This study revealed one of the key issues relating to current disability awareness-raising strategies was the fact that disability awareness and disability awareness-raising remain relatively under-developed aspects of addressing issues of disability in Indonesia. It was almost impossible to find a formal and explicit definition of this, or research or reports on this topic.

This is concerning because Indonesia has incorporated the ratification of the CRPD into Law Number 19 (2011) concerning the legalisation of CRPD, wherein raising awareness of PWD is considered to be one of the most important aspects of the CRPD. It is officially reinforced in Article 8, which stipulates the objectives and measures to achieve disability awareness. It does not straightforwardly define disability awareness, but states it in somewhat broad and vague terms. Consequently, as described in Chapter Two, disability awareness is inferred as something related to the common ways in which PWD are viewed and treated. This means that disability awareness is closely connected with the attitudes and behaviours of the society toward PWD.

- Disability awareness.

This study reveals that disability awareness is the state or condition in which the public accept PWD in Indonesia. This concept can basically be positive or

negative, and it related to the gap between existing reality and expectations. This means, negative disability awareness related with the existing reality of disability awareness as identified and experienced by the research participants in this study as Indonesian PWD. While, positive disability awareness related with the condition which expected by and strived for Indonesian PWD through disability awareness-raising strategies.

Hence, this study found that disability awareness in Indonesia is still negative due to the realities of people's attitudes, behaviours and mindsets remaining predominantly based on harmful myths and assumptions. Myths, according to research participants - especially the CRG - are false beliefs that are not based on knowledge, evidence or experiences but are commonly perpetuated through socialisation. This finding is consistent with what has been documented in research reports from around the world; for example, in Japan (Saito & Ishiyama, 2005), in Thailand (Naemiratch & Manderson, 2009), in India (Buckingham, 2011), in Ghana, Africa (Naami & Hayashi, 2012), in Uganda, Africa (Katsui, 2008; Katsui & Kumpuvuori, 2008), in Central Asia and Zambia (Katsui & Koistinen, 2008), and in South Africa (Heap, Lorenzo, & Thomas, 2009). These studies reported that negative awareness of disability is due to negative public attitudes and behaviours. The finding is also consistent with the study of a British social attitude survey in 2009 which presumed that negative attitudes and behaviours toward certain issues come from people not having adequate knowledge of an issue (Stanlland, 2011).

However, this study also reveals that disability awareness aspires to be positive. This is due to the research participants' concept of disability awareness which involves a condition where the public accept Indonesian PWD as integral part of their society, which consist five key elements: as part of diversity in Indonesia, and as individuals who have needs, rights, capabilities and the capacity to contribute to society. This finding is consistent with a previous study which stated disability awareness as a positive attitude and increased empathy toward PWD (Columna *et al.*, 2009).

In sum, disability awareness is a crucial concept that underpins and emerges in this study. It is fundamental to the strategy of addressing the existing negative realities of discrimination and social exclusion faced by Indonesian PWD.

- Disability awareness raising.

Furthermore, this present study identifies that disability awareness will mainly be realised through activities or efforts, namely disability awareness raising. The intent is to change people's mindsets, which are predominantly based on harmful myths and assumptions about what a disability is, who PWD are, and what it is like to live with a disability. Disability awareness raising in this study is described as the activities or efforts which provide information exchange to counter societal and attitudinal barriers due to misinformation, misperception and misunderstanding caused by myths about disability and PWD. It involves activities or efforts to achieve a condition filled with positive attitudes and public acceptance toward PWD. This finding is supported in the literature (see Sayers, 2006, p. vii)

Findings of this study which clearly present the definitions of disability awareness and disability awareness raising, were in contrast to previous research that discussed, and put 'disability awareness' in their titles but did not directly state their definition of disability awareness (for example, see Fittipaldi-Wert & Brock, 2007; Forrest, 2007; Folley *et al.*, 2007; Ison *et al.*, 2010; Mc-Pherson, 2011; Tavares, 2011).

b. Existing disability awareness raising strategy in Indonesia

This study confirms that current disability awareness-raising strategies in Indonesia associated are almost solely with International Disabled Day. It mostly comes in the events or format of an annual ceremony event to celebrate the day. Sometimes these events accompanied by a public campaign such as: 'special edition' of articles or reports in magazines or newspapers, or TV shows highlighting disability issues or featuring Indonesian PWD, an exhibition of art pieces by Indonesian artists with

disabilities, sport events for Indonesian PWD who love and are able to do certain sports, or sport competitions such as the Paralympics by Indonesian athletes with disabilities.

The participants of this study considered this to be disappointing, because it reflects how disability issues have not been a priority among the general public and government. Even though the event appears to be attracting more attention each year, the participants believe that it is not legitimate because it is not directly associated with increasing public awareness of Indonesian PWD issues. This finding is consistent with the literature, as, for example, Fuad (2009) states that ‘the ritual annual conduct of an international day of PWD on December 3rd ... has done little to change the lived experience of PWD’.

The existing disability awareness-raising strategy, which is one day a year’s event has weakness in raising positive awareness. Mostly, due to limited coverage, it has not been sufficient to make the public aware that disability is not only an issue for the individual with disability and their family, but a social problem in which members of the society contribute to the barriers PWD continue to face. After the event, members of the public easily forget what was experienced or conveyed during the event, and they naturally revert to their understanding that ‘disability is not my businesses’.

As a result, Indonesian PWD still experience discrimination in terms of education, trying to have meaningful interpersonal relationships, and making a living. For the CRG participants, who are still experiencing discrimination despite overcoming barriers and gaining high level of educations, this is disappointing and contradicts the knowledge and experience they gained overseas during their studies. They asserted that it should be conducted in a format that makes it possible to reach a wide cross section of the population, and it has to be conducted regularly, on an ongoing basis, and be sustained.

c. Existing disability awareness audio-visual media in Indonesia

This study reveals that a lack of various disability awareness-raising strategies signals a need to establish an Indonesian disability awareness programme that is sustainable and able to reach a wider population. There was agreement among the CRG participants and other participants that a disability awareness-raising strategy, equipped with a disability awareness video, would be effective and would suit the criteria well. As confirmed by Cruze (2007); von Krogh (2010) and Swartz *et al.*, 2010) this study argued that a video has the capacity to improve people's understanding of the lives of PWD through the visualisation of meaningful images and sounds in a way that accommodates the voices of people living with disability in Indonesia to refute the negative, deep-rooted beliefs perpetuated through inter-generational internalisation. Raising positive disability awareness is a challenging process in which the media plays a vital role.

However, most of the existing disability awareness videos currently available online, as recommended by Connor and Bejoian (2006), Safran (2000) and Bromley (2008), do not discuss the issue in an Indonesian context, nor are they in the Indonesian language. Generally, these videos are delivered in English or other languages with English subtitles. This limits the direct use of these videos for disability awareness-raising programmes in Indonesia. Although English is one of the foreign languages taught in school, most Indonesian people do not speak English daily and are unfamiliar with non-Indonesian contexts. Using videos with non-Indonesian languages and contexts may not adequately address the lives and experiences of Indonesian PWD. Applying non-Indonesian contexts and languages in videos to raise disability awareness in Indonesia requires careful modification and specific preparation to avoid misinformation and misunderstanding among audiences.

The research participants believe that the limitations of the existing disability awareness videos currently available online indicate that the development of a disability awareness video in Indonesian to communicate disability issues

and the lives of PWD in Indonesia was needed to complement disability awareness-raising strategies. This idea is similar to a previous PAR (Kreitzer *et al.*, 2009), which collaboratively produced a public education video as an awareness-raising strategy for social work in Ghana, West Africa (pp. 159-160). Another study involved 'participatory research using video in Fogo Island, Canada in the late 1960s which was created as a tool to document social problems for social change, and to use the audio-visual process to raise awareness' (Hume-Cook *et al.*, 2010, p. 161).

6.3. The development of a disability awareness video as a disability awareness-raising strategies proposed by the research participants.

a. Disability awareness and the social semiotic of disability

As a result of the current state of disability awareness the PAR process resulted in an agreement to develop an Indonesian specific disability awareness video. This confirmed disability awareness' strong relationship with the social semiotics of disability (Woodwill, 1994, p. 204), which refers to negative experiences resulting from negative images disseminated through the media (both printed and audio-visual). Participants did not specifically refer to the social semiotics of disability, but they revealed how various circumstances and social constructions of PWD create visual understandings or images of people with disabilities. Social semiotics are described as:

A powerful tool in the analysis of the situation and social construction of peoples with disabilities. It shows us how different appearances that are learnt from an early age by people both with and without disabilities can create conscious and unconscious images of what it means to be disabled, and how these representations can perpetuate oppression and helplessness (Woodill, 1994, p. 219).

The media has the potential to play an important role in constructing positive awareness, however, it currently does not do so. Ableism prompts the media to perpetuate negative images of PWD (Krogh, 2010, p. 380).

This study supports the results of previous studies (e.g. Connor & Bejoian, 2006; Ciot & Hove, 2010; Mitchell, 2008; Saito & Ishiyama, 2005; Safran, 2000; Schwatz, *et al.*, 2010; Soffer, *et al.*, 2010) that the representation of individuals with disabilities in mass media tends to be limited and negative. This makes raising positive disability awareness a challenging process because the media still does not recognise their social responsibility (Isaac, *et al.*, 2010, p. 629). The research participants noted that:

Media, such as television, movies and books, often deliver wrong messages about disability that exploit disability conditions, or otherwise describe disproportional superhuman capabilities. This happens because they don't consult with PWD or DPOs; and are not aware of the stigma that results from the damaging myths.

These misleading messages are more dominant because, as argued by another participant, *'the majority of Indonesians with disabilities do not have the channel to voice their life experiences in order to provide actual evidence about what disability means and what it's like to live with disability'*.

Moreover, the participants of this PhD PAR were disappointed that the disability awareness videos found on free online sites, such as YouTube, tend to visualise PWD as objects, further continuing the inaccurate visual stereotypes of PWD as discussed in the previous references and research (Ciot & Hove, 2010; Mitchell, 2008; Saito & Ishiyama, 2005; Safran, 2000; Schwatz *et al.*, 2010; Soffer *et al.*, 2010).

They gave an example of a disappointing disability awareness video from YouTube that was a video titled "Rotary Nepal Disability Awareness Video: Shall we worship" (Rotary Nepal & TRIFC, 2009). It seemed informative in delivering a message about the rights of PWD to accessibility and to perform

their religious rituals. This video presented a woman who is a wheelchair user whose access to a house of worship is limited due to a physical barrier in the form of steps. This video, according to the majority of the CRG participants, was a good public service announcement (PSA) video; yet, it could not be fully considered a disability awareness video.

The participants insisted that it was not a disability awareness video for a number reasons. Firstly, the video did not present the PWD positively. Secondly, the informative message in the video was delivered by a public figure, not by the person with disability. In contrast, the woman with disability in the video did not say anything and was not actively involved in delivering the message. For examples asking questions or asking for help. In consequent, the participants of this study concluded that the video is not a disability awareness video because it delivered a message about physical barriers for people with disabilities, but with converse effect of perpetuating the visualisation which represent PWD as weak, needy and incapable.

These representations are consistent with the findings from a previous study, which revealed that dominant visualisations in the media perpetuate myths of disability as a personal tragedy and dependency (Saito & Ishiyama, 2005; Safran, 2000; Schwatz, *et al.*, 2010; Rimmerman, Blanck & Hill, 2010). Thus, finding of this study confirmed that the public's negative understanding about disability and PWD influenced the way PWD were presented in the video, or the media - in general.

In contrast, participants argued that the videos could have incorporated a more positive message. For example, when the PWD had difficulties with the steps, she could have asked whether there was an alternative way to enter the building. In case there was no entrance without steps, she could ask another person to get a piece of wood to make a ramp. She could also ask the others to lift her wheelchair by giving instructions on how to do it safely.

As described in Chapter One, the collaboration between the DSC-UI and a local television station in Jakarta on video documentary project yielded

dissatisfaction due to the videos were not considered to be disability awareness videos by the DSC-UI. Through this study, I then can understand the reason of the dissatisfaction.

The participants argued that although these videos about Indonesian people with disabilities, in an Indonesian context and in Indonesian, were not disability awareness videos due to a number reasons. Firstly, the videos mainly document inspiring personal stories of Indonesian people with disabilities. This means that the videos tend to visualise Indonesian PWD as high-achieving individuals who are able to handle all barriers with their own effort and persistence. In related literature, they are labelled as '(super) heroes' (Ciot & Hove, 2010, p. 526; Schwatz, *et al.*, 2010, p. 841; von Krogh, 2010, p. 383). This also means the informative message of this video was not adequate. Secondly, the visualisation of these inspiring stories is considered inaccurate, as the videos do not depict other parties helping the PWD to overcome barriers. Videos like these, which romanticise people with disabilities, make the audience fascinated with the Indonesian PWD featured in the video. In contrast, the DSC-UI insisted that what is really needed is not merely inspiring videos. Instead, videos which are able to enhance the audience's knowledge and understanding are necessary so they can bring forth changes in the community in order to remove barriers that have so far led to discrimination against people with disabilities.

With regard to the video messages, YouTube videos and DSC_UI videos typically deliver only one or two types of messages. The most common messages are informative and instructional. For example, the video from Nepal (discussed above) delivers informative and affirmative messages, while the DSC-UI video contains mostly informative messages. A majority of the CRG participants hoped for a disability awareness video that contains all three messages: informative, instructional and affirmative. With such a video, it was expected that the audience would obtain an adequate understanding of disability and people living with disability. It was also expected that the audience would understand how to communicate and interact with people

with disabilities, and how to help them, as well as the reasons why understanding is important.

Therefore, the CRG participants believed that the best disability awareness video for the Indonesian context was a video that is developed based on the Social Model. The underpinning reason is that, under this model, PWD have to be the main actor. They have to take an active role in the process of video-making; their onscreen representation needs to be positive with positive/acceptable language; and the video should cover the three types of messages: informative, instructive, and affirmative.

Bearing the Social Model of disability in mind, the participants believe that the video does not perpetuate or reinforce existing stereotypes based on the dominant model. The model of disability, which suggest that PWD are incapable or in contrast as 'heroes' or extraordinary individuals.

In sum, this study was successfully yielded the disability awareness video, making guidelines and an Indonesian disability awareness video based on those guidelines. These are different from the previous studies (Ison, 2010; Rillota & Nettelback, 2007; and Tavares, 2011), which did not develop the video guidelines and the disability awareness video. They only used the videos that have been available for them to be used in their evaluative studies on disability awareness.

The findings are in contrast with previous studies by Salend (2005), Connor & Bejoian (2006), and Safran (2000) that provided guidelines for **using** videos, DVDs, films to teach about disability. This study yielded guidelines for **making** a disability awareness video. These are the first guidelines which were created by Indonesian PWD based on the Social Model of disability through a PAR project in an Indonesian context. These findings augmented previous studies regarding PAR with video (Hume-Cook *et al.*, 2010; Kreitzer *et al.*, 2009; Parr, 2007) which did not directly or specifically describe the video-making guidelines.

b. Degree of participant involvement in PAR with video

With regard to realistic participation in PAR, which is illustrated using an adapted version of Fajerman and Tredesen's six-degree model of participant involvement in PAR (Radermacher, 2006, p. 27) (see Figure 3.3 in Chapter Three), this study involved model participation 'researcher-initiated, shared decisions with participants' (Radermacher, 2006, p. 27). I initiated this PAR with a research topic that reflected my concern as I described in Chapter One. I developed it to be a PhD research proposal, where I needed to include a literature review which consisted a rationale for conducting the research, the methodology and methods, and also specified the budget and timeline needed to conduct this study. The situation in which I initiated this PhD PAR is similar and even confirms the experiences of Maguire (1987), Valade (2004), Radermacher (2006), Katsui and Koistinen (2008), McFarlane and Hansen (2010) and Ollerton (2013). It is also similar to previous researcher-initiated studies that were not PhD studies, such as those conducted by Hester Parr (Parr, 2007), Kreitzer (2009), and Sara Kindon (Hume-Cook *et al.*, 2010).

However, the views of Indonesian PWD who were the research participants in this study were fully considered. They were authorities on their own lived experience. They were experts on their lives, experiences, feelings and views. They were interested and motivated to be actively engaged in this study and share a wide range of invaluable knowledge and skills. They were involved with varying meaningful levels of participation following the specific conditions of each participant. They were involved in taking the decisions related to the research process as co-researcher and collaborator who provided expertise, guidance and dialogue for this study. Their various modes of participation during this research process were confirmed by the literature (see Kidd & Krall, 2005, p. 1889; Katsui & Koistinen, 2008, p. 753; Kindon *et al.*, 2010, p. 15).

Moreover, as to the degree of participation, the video-making process revealed the uniqueness of this study. The post-production or editing stage of

this study became iterative into three cycles of PAR process. This stage engaged three different participants, who were involved consecutively due to their incompatible schedules. This is the uniqueness of this study compared to what was reported in three articles by Parr (2007), Kreitzer *et al.* (2009), and Hume-Cook *et al.* (2010), whose the video editing processes in those three studies could be conducted together/at one time because their research participants could invest their time as required. Nevertheless, the most important aspect as to degree of participation in the video-making process of this study was to reach the expectation of accommodating the aspirations of the research participants who controlled how 'positive disability awareness' messages were represented in the scenes of the video.

In the case of various forms and modes of participation, this study is similar to a PhD PAR carried out in non-Western regions: Central Asia and Zambia, Africa (Katsui & Koistinen, 2008) in which PWD who were the research participants had to go to work; therefore, they could not invest their time fully during the research process. Therefore, this study still performed credible research (Lincoln & Guba, 2011, p. 296) as it implemented the Fajerman and Tredeesen's degree of participation (Radermacher, 2006, p. 27), the ethical PAR principle that respect the participants (Manzo & Brightbill, 2010, p.33), and PAR characteristics: "treating diversity as enrichment to research process" (Kindon *et al.*, 2010, p. 14).

c. The video-making process and PAR process

As to the video making and PAR process, this study has its own uniqueness at two aspects: the video/film¹ making crew, and the implementation process of video making stage with the four stages of PAR, moreover when the research process reveals the need to repeat into three cycles.

¹ See Chapter Three in the last paragraph before sub-heading 3.2 for the explanation of the definition of, and terminologies for video and film which are applied interchangeably.

- The video making crew

The video making process of this study is different from the studies of Hester Parr (2007) and Hume-Cook (2010), which was mostly regarding the video making crew. In their research projects, researchers and research participants become the direct film makers – after being trained by professional film maker previously. In contrast, in this study we were not able to implement this due to time and financial constraints. For this study we only had 8 consecutive weeks to make the video. In contrast, Parr (2007) and Hume-cook (2010) spent 12 months. Nevertheless, this does not necessarily mean that this study is less valid compared to those two studies. As Hume-cook states: ‘the process can and does take many forms because it has to be adapted to suit the available timeframe, and also depends on other matters, such as the level of funding and the purpose of initiative of the video making’. The video-making process in this study involved the assistance of broadcasting students from a vocational programme at the University of Indonesia. This is quite similar to a PAR with video conducted in Ghana by Kreitzer *et al.* (2009), in which they were supported by individuals from a local television station.

- The implementation of video making stage with the four stages of PAR, during the cyclical research process.

Journal articles about PAR with video (Parr, 2007; Kreitzer *et al.*, 2009; Hume-Cook *et al.*, 2010) do not directly describe link between the stages of video/film making with the stages of PAR, despite these articles discussing participatory/collaborative research. Therefore, there was an opportunity for this study to explain these links and to make an original contribution to knowledge about PAR and video making.

As indicated in Chapter Three, PAR’s recursive cycles have observing, reflecting, planning and acting stages. Then, Chapter Five presented the video-making process as comprising of pre-production, production and post-production stages. However, this study found that when the video making process juxtaposed to the PAR process:

- 1) The pre-production stage relates not only to the planning stage but also to the observation and reflection stages of PAR. This study revealed that pre-production not only consists of technical preparation, but most importantly it also involves substantial preparation, which is conducted in the observation and reflection stage, and which became the basis for the technical preparation.
- 2) The production and post-production stages (filming/video shooting and editing) relate to action stage of PAR.
- 3) The whole process of intentional, focused video making is a scientific research process, and is not a programme activity without any scientific base. It is also not a peripheral process.

The following Figure 6.3 presents a basic or simplified explanation (compared to the real complexity in the field) of the implementation of the video-making process and PAR process in this study. Especially in the first of three cycles of PAR process, namely the video making cycle (see Chapter Four for detailed description of the PAR cycles in this study)

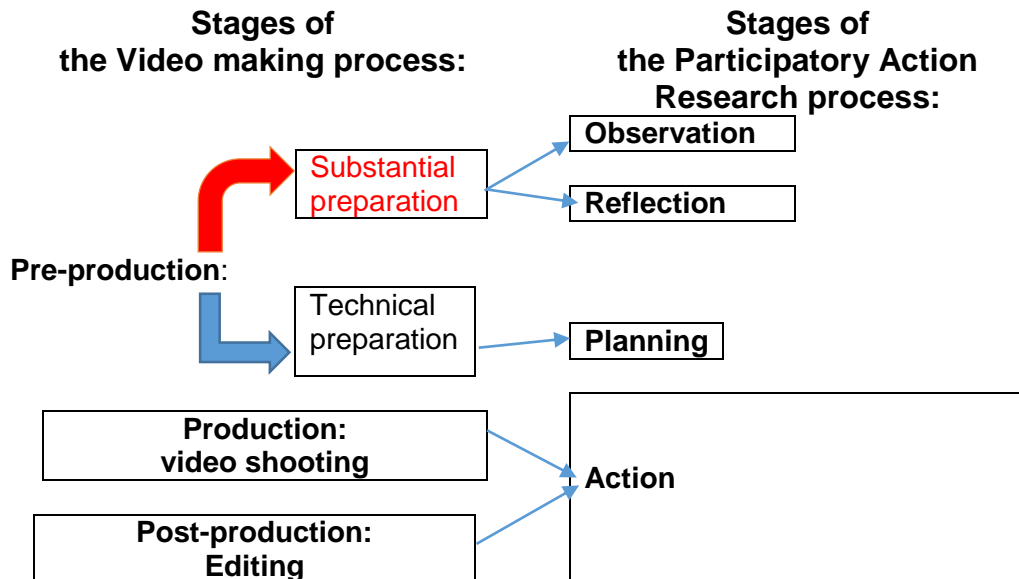


Figure 6.3. Stages of the video making process and stages of the PAR process in this study

In sum, the pre-production stage is not only about discussing technical matters related to preparing the video shoot, it is also about involving data collection as the basis of video-making, which is equivalent to the

observation stage of PAR. Thus, the pre-production stage are involved the observation, reflection, and planning stages of PAR. The production and post-production phases (video shooting/filming, recording and editing) are the action stages of PAR.

It is unique and interesting that in this study, especially in the first of three cycles of PAR process, the video-making stage consisted of four stages. This finding is different from the research conducted by Parr (2007), which only involved three stages, namely, pre-production, production and post-production.

Another uniqueness of this study is that in the second and third cycles of PAR process, the video-making stage only involved two stages: pre-production and post-production. There were no production stage in term of shooting/filming the video participants in the field, due to time constraints, limited opportunities and financial resources. These finding, that the first cycle consisted of four stages and the second and third cycles consisted only two stages of the video making process, were consistent with previous literature which concluded that PAR iterative cycles "actually are complicated to demonstrate with ease due to the high level of flexibility in PAR" (Quixley, 2008, p. 9). In addition, this also demonstrated what has been found in the previous studies that PAR are fluid, co-created and idiosyncratic (Ollerton & Horsfall, 2013, p. 620).

Summary of chapter

This chapter has presented the key contributions of this Indonesian specific PAR study with PWD. It highlights some similarities with other literature from Western nations. However, there also unique cultural and contextual considerations in Indonesia highlighted by the study.

The contribution of a video that was driven by the lived experience of PWD in Indonesia represents an important addition practically as well as the outcome of a PAR process. Other methods would not have led to this outcome.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

This PhD research project involved collaboration with a purposive sample of Indonesian people with disabilities (PWD) to achieve the research objectives. This study is a unique and important contribution to understanding life for PWD in contemporary Indonesia.

This chapter describes the conclusion, the key outcomes, the limitations of the study, suggestions for future research, and some final recommendations.

7.1 Conclusion and key outcomes

Most people normatively know that discrimination is unlawful. Unfortunately, as explained by most Indonesian PWD, including the research participants, various forms of discrimination still exist in today's society, despite the Indonesian Government having ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). There are more cases of discrimination, rejection, low expectations and exclusion of Indonesian PWD in comparison to their widely publicised achievements, talents and personal success stories.

Thus, according to the research participants, current disability awareness in Indonesia is still overwhelmingly negative. This is due to the barriers faced by PWD in their daily lives, which are rooted in the inappropriate attitudes and behaviours of the majority of society. These include a fear of being infected with or inheriting impairments, patronising pity and sorrow, and the idea that PWD ought to feel ashamed or sinful. PWD have been socially constructed as passive, incapable, and a burden on Indonesian society. This negative awareness leads to negative practices and policies, which are manifest in the form of inaccessible social and physical environments, and a lack of accurate

information or knowledge about disability and PWD. Consequently, these prevent the social inclusion of PWD. This is confirmed by a study on disability in low-income countries, which concluded that the inclusion of PWD is one of the most essential requirements for the realisation of universal human rights (Isaac *et al.*, 2010, p. 629).

Therefore, the research participants agreed on the importance of raising positive disability awareness. It is needed to overcome the existing negative awareness in the public toward Indonesians with disabilities. They proposed and emphasised that a locally developed and produced video in the Indonesian context was the most appropriate strategy for disability awareness raising.

Accordingly, the research participants who formed part of the critical research group (CRG) formulated guidelines on generating a disability awareness video for Indonesians. The guidelines covered several aspects: the target, the type, the media, the format, the duration and the actors, as well as the purpose, theme and contents of the video (see Table 5.2 in Chapter Five). The findings of this study demonstrate that these detailed guidelines led to a smooth video-making process.

The leading mandate from the guidelines was that the disability awareness video must include three types of message: informative, instructive or educational, and affirmative messages. In the video produced for this study, the informative messages involved delivering information so that people have a better understanding of diversity, disability and PWD, and the roles, rights and activities of PWD. Through the instructive messages, the video taught the audience how to communicate and interact with PWD. The affirmative messages in the video strengthened positive disability awareness, due to its favourable and positive suggestions. Two affirmative messages in the video - 'it is crucial for the audience to be involved in welcoming people with disability

into society' and 'creating a welcoming community is a social responsibility for all members of society' – were confirmed by all participants of this study as significant. These affirmative messages were consistent with a statement in a conference paper by Indian scholars (Isaac *et al.*, 2010, p. 629) that emphasises the need to change the mindset of people to accept and respect PWD.

Society should be dynamic enough to accept all difference ... It is the duty of each member of society to respect the rights of disabled members of society ... disability also impacts the whole community. The cost of excluding PWD from taking an active part in community life is high and has to be borne by society (p. 630).

Furthermore, the disability awareness video, which included these three types of message, provided knowledge and values, skills and attitudes to be internalised by the audience. The research participants believed that these would raise positive disability awareness, understanding and acceptance of Indonesian PWD.

There were a number of key outcomes produced in this study which were organised into six sections: the conceptualisation of disability awareness, disability awareness-raising and a disability awareness video; the development of a disability awareness video; the PAR process and the video-making process; lessons learned from employing PAR; the challenges of performing PhD PAR; and engagement with Indonesian PWD.

a. The conceptualisation of disability awareness, disability awareness-raising and a disability awareness video

This study commenced with a broad and vague understanding of the formal definitions of disability awareness and disability awareness videos. The CRPD stipulates the objectives and measures to achieve disability awareness, but does not explicitly state an official or formal definition of this concept. Moreover, as described in Chapter Two, I did not find any literature which specifically addressed the definition of disability awareness and the meaning of disability awareness videos. However, conducting collaborative research with engaging research participants enabled me to finally achieve important understandings of these three relevant key terms, which became one of the key outcomes of this study, namely disability awareness, disability awareness-raising, and the creation of a disability awareness video.

- a.1 Disability awareness is basically defined as a state or condition of acceptance by the public toward PWD, which is characterised by at least five elements of acceptance.

This study identified that there is a gap between current disability awareness and the expected disability awareness by Indonesian PWD. Consequently, there are negative and positive forms of disability awareness. This study found that current disability awareness is still negative due to PWD being socially constructed as passive, incapable and a burden for Indonesian society. In contrast, however, positive disability awareness is expected by Indonesian PWD. This is a condition where PWD are accepted by Indonesian society as a natural part of diversity and an integral part of their society, and who have common needs, equal rights, significant capabilities, a valuable existence, and can make contributions.

- a.2 Disability awareness-raising refers to the activities or efforts to counter barriers arising from misinformation, misperceptions and misunderstanding due to myths about disability and people with disabilities. The intention is to change people's mindsets, counter negative disability awareness, and realise positive disability awareness.

This is related to the concept of awareness-raising presented at the beginning of this thesis, which is defined as a process which creates opportunities for information exchange (Sayers, 2006, p. vii).

- a.3 A disability awareness video (especially for an Indonesian context) is a video that is developed based on the Social Model of disability, so that PWD play an active role in the video-making process and are the main actors (and are not secondary or supporting characters). Their portrayal needs to be positive, with positive and acceptable language, and the video should convey three types of message – informative, instructive and affirmative messages – to cover three important purposes, namely, knowledge, skills and values.

- Informative messages are messages that provide a reliable illustration of the similarities between PWD and society, and include explanations of what a disability is and who a person with a disability is. This information helps people to have a better understanding of diversity, disability and PWD, and the roles, rights and activities of PWD.
- Instructive messages are messages to educate the audience on how to deal with people with disabilities appropriately and respectfully. This includes messages which teach how to communicate and interact with PWD.
- Affirmative messages are favourable and positive messages that disconfirm myths and negative understandings of disability held by

the majority of society. These messages express respect, approval, and confirmation of positive awareness of PWD and disability.

Establishing clear definitions of disability awareness, disability awareness raising and disability awareness videos are important original contributions of this study for the area of disability studies, and studies using participatory action research in a non-Western context such as Indonesia. This study revealed that there is very little non-Western documentation on disability, especially in Indonesia, that has reached the academic community at the international level (as described in Section 2.1 of Chapter One, and Section 3.1.6, point b. of Chapter Three).

b. The development of a disability awareness video

The development of a disability awareness video in this study offered an original contribution to the lack of media on disability and PWD in Indonesia specifically designed for disability awareness for and on Indonesia. This is in comparison with the plethora of audio-visual media that can be used to support disability awareness-raising in Western contexts, such as those reported by Bromley (2009), Columa *et al.* (2009), Connor and Bejoian (2006), Mitchell (2008), Safran (2000) and Salend (2005).

This study developed guidelines for the creation of positive disability awareness videos for future media development, and produced a 13-minute-long digital video. The video portrayed how three Indonesian people with disabilities with different impairments live on a daily basis, and it was delivered in the Indonesian language.

The guidelines and the video were driven and produced by Indonesian people with disabilities with the spirit and mindset of the Social Model of disability and as a creative product of PAR. These complemented findings from other studies

on disability awareness training which included audio-visual material such as films and videos (Ison *et al.*, 2010; Shapiro, 2000; Tavares, 2011).

c. The PAR process and the video making process

Another original contribution of this study was the development of an understanding of the juxtaposition between the implementation of PAR and the video-making process, as described in Chapter Six. This finding supports what had been previously agreed — that the video-making process comprises three stages - pre-production, production and post-production (Parr, 2007) - and the PAR process consists of four iterative stages: observing, reflecting, planning and acting.

As described in Chapter Six, this study revealed that pre-production not only consists of technical preparation, but more importantly also involves substantial preparation, which is conducted in the observation and reflection stages of PAR. This became the basis for the technical preparation, which was carried out in the planning stage of PAR. The production (filming/video shoot) and post-production (editing) stages were carried out in the action stage of PAR (see Figure 6.3 in Chapter Six for an illustration of this stage). This finding is different from the study conducted by Parr (2007), which only involved three stages, namely, pre-production, production and post-production. Moreover, Kreitzer *et al.* (2009) and Hume-Cook *et al.* (2010) did not directly or specifically describe their video-making stages.

However, this study was consistent with previous studies (Hume-Cook *et al.*, 2010; Kreitzer *et al.*, 2009; Parr, 2007), which concluded that the whole process of video-making is a scientific research process, and is not a programme

activity without any scientific base. It is also not a peripheral process. In this study, the PWD who were the research participants and co-researchers were predominantly engaged and fully involved in the decisions of choosing video as a disability awareness-raising strategy, creating guidelines for the video (the observing and reflecting stages), preparing the video (planning stage), the video shoot, and its final production (the acting stage).

d. Lessons learned from employing PAR

Besides having been a well-suited approach to address the research objectives, PAR also offered advantages to both the researcher and research participants. These benefits were mainly in the form of lessons learned throughout the research process. I learned a lot, as a researcher, an advocate, and as a human being. I documented the following five lessons:

- d.1 The first lesson was **respect**, which is derived from the philosophy of valuing all people (Wolfensberger, 1992). Collaborating with 43 individuals was such a valuable learning experience. We had the opportunity to practise this value directly throughout the research process. By respecting each other, both the researcher and research participants had the opportunity to accept, learn, and share various strengths and weaknesses (as described in the reflection box in the research process section in Chapter Four and in the video development process section in Chapter Five).
- d.2 The second lesson was **flexibility**. Both the researchers and research participants also had the opportunity to practise flexibility when dealing with a number of unexpected incidents, as described in Chapter Four. One example was when the CRG participants expressed their hope that all Indonesians with disabilities could articulate all three kinds of message

in the video. However, a lack of resources and time constraints made it impossible to meet all expectations. With flexibility based on mutual respect, we compromised by adding a narrator's voice and text to the video. Having a narrator was believed to be the best method to assist with articulating affirmative messages. A similar approach was reported by Parr (2007), who performed a collaborative film-making process and had a narrator. Her research featured four different mental health communities in three different cities in Scotland. Similar to Hester Parr, in this study we were also concerned with making a video/film that depicted a very positive representation of marginalised people and their activities, although we did not have any experience with video/film production.

On the other hand, flexibility in conducting PAR also yielded its iterative cycles of observing, reflecting, planning and acting, which are in fact complicated to demonstrate with ease as depicted in a simplified working PAR model (Quixley, 2008, pp. 9-10) (see Figure 3.2 in Chapter Three).

- d.3 The third lesson was an opportunity to apply **the pearl of wisdom: 'From little things, big things grow'**. Changing the current dominant individual model of disability in Indonesia into the Social Model to fight against discrimination and social injustice faced by PWD was a challenging and complicated task. In other words, it is what is referred to as a 'big thing'. This study confirmed that such a task should start from small yet serious and consistent efforts. We believe this study is a significant 'little thing'. Through collaboration with 43 Indonesian PWD who were articulate, enthusiastic, and have valuable lived experiences, this study demonstrated the direct practice or implementation of social inclusion. This study also made a serious attempt to develop a disability awareness video as a disability awareness-raising strategy to combat current negative disability awareness. The guidelines, the video and this thesis

are critical 'little things' which contribute directly to the lack of material and audio-visual media on disability awareness in an Indonesian context, as discussed in Section 2.4.4 and 2.5.5 in Chapter Two.

- d.4 The fourth lesson was the **courage to take risks in performing PAR**. I began to understand what a PAR expert, Rajesh Tandon, claimed: that it is 'better to take a risk than to do nothing or to wait and want to do it right' (McGuire, 1987). When conducting the literature review, I discovered a number of unfavourable challenges, such as: the scarcity of PAR related to disability issues and PWD in non-Western contexts, such as Indonesia; the fact that PAR does not offer one particular research strategy and offers a high level of flexibility; and the fact that PAR is an inherently time-intensive activity, and therefore the time frame and budget often become an issue in many PAR PhD projects. However, among many challenges, with the terrific commitment and forceful determination of the participants and researchers, this study completed the process of PAR and accomplished the three objectives of this study.
- d.5 I managed to understand the meaning of the idiom, '**learning is a never-ending journey**'. I realised that the learning process is still ongoing even though the research has been completed. I have learned so much from the participants of this study about fundamental life values such as the struggle for survival, how to adjust to unfavourable situations and how to turn limitations into strengths. It is amazing to think how much I have learned from each of the participants and how much I grew during the research process with, from and for all of them. Furthermore, it made me aware of the need to learn more and more from PWD, in order to be able to continue working with them in the future.

e. The challenges of performing PhD PAR

During this study, as described in Chapter Four, I concurrently exercised at least three different roles with limited resources, time and finances. I experienced the challenge of juggling the various demands and priorities of being a participatory action researcher, the producer of the video, and an organiser of the video showing sessions.

Conducting this PhD PAR with video, as a novice participatory action researcher, I learnt that 'PAR is fluid and idiosyncratic' as confirmed by a previous study by Ollerton and Horsfall (2013, p. 620). This was due to two reasons: First, PAR does not offer one particular research approach, as it 'represent[s] a counter hegemonic approach to knowledge production' (Kindon *et al.*, 2010, p. 9). Secondly, 'the high level of flexibility in PAR makes its iterative cycles in fact complicated to demonstrate with ease' (Quixley, 2008, p. 9). Finally, I experienced a challenge that was confirmed by a previous PhD PAR, Valade, who explained that 'each PAR will look and move differently with different groups, contexts, people involved, and affected, and issues confronted' (2004, p. 71).

The experience and tips from previous PhD PAR (Klocker, 2012) have encouraged me to persevere with this study. Moreover, I was able to overcome these challenges due to the full commitment and strong determination of all of the researchers. As co-researchers, the participants were highly enthusiastic and actively involved in providing guidance and dialogue. In addition, I was able to perform this PhD PAR due to the great supervision and support from my thesis committees.

f. Engagement with Indonesian PWD

This study has the specific outcome of contributing to disability studies with regard to engagement with participants. This study was conducted in Indonesia. The fact that the participants and researcher had the same background — we were all Indonesians — made building rapport and collaboration smoother. The participants of this study and I felt a sense of trust and attachment as parties who believed in the importance of presenting positive images and accurate information on Indonesian PWD to raise positive disability awareness. This was in contrast with the experience of previous PhD PARs conducted by Katsui and Koistinen (2008), Klocker (2011) and Read (2012), who might be considered as outsiders or foreigners to their participants (as described in point c, Section 3.1.6 of Chapter Three).

Furthermore, the Indonesian PWD who participated in this study were terrific mentors for me as a novice participatory action researcher. They were very articulate and enthusiastic. Although we had to face many risks and challenges, we were able to accomplish all three objectives within the expected time frame.

7.2. Limitations and Future Research Direction

This study had the following limitations:

- a. The types of impairment and disability.

A limited budget and limited time available for this study restricted the variety of impairments and disabilities that were able to be included in this study. Even though the resources were not adequate, with great effort to develop good rapport, this project had invaluable resources — namely, the high commitment of the participants. Future research should engage a wider variety of impairments and disabilities.

This thesis makes a critical comment on the capacities of this study's participants compared to other disabilities, especially intellectual and developmental disabilities (IDD). These groups, in almost all jurisdictions, represent the most challenging issues and arguably, the UNCRPD does not adequately incorporate them in the Convention. In Chapters One and Three, I have described my justification for focusing on highly competent PWD for this study. However, it does not mean that this study and I consider that Indonesian people with IDD should be overlooked and not considered as appropriate research participants. This is merely related to the limitation of resources. Therefore, this thesis suggests that an important future research agenda is one that includes people with IDD.

b. The audience.

Considering the complexities of disability issues and a number of limitations, the disability awareness guidelines developed in this study were mainly aimed at a non-disabled student audience (see Chapter Five, Section 5.3.1.3 and Table 5.2, 'The CRG Guidelines for a Disability Awareness Video'). Future research should develop disability awareness guidelines and videos which target a wider audience, including influential people such as religious and cultural leaders, as well as government apparatus (policy makers).

c. The delivery strategy.

The disability awareness video produced in this study was disseminated by providing the opportunity to watch the video. To foster public awareness of disability and people with disabilities, disability awareness-raising strategies in the future should be combined with training sessions, interactive discussions, and other initiatives which cover a wider audience and develop a deeper understanding of the relevant issues.

7.3. Recommendations

The findings of this research have important implications for the practice and services that support PWD in Indonesia.

- The government, DPOs (disabled people organisations) and civil society (including non-government organisations) should work hand-in-hand more intensively to eradicate the dominance of harmful cultural beliefs toward Indonesian people with disabilities.
- It is imperative for the government, DPOs and civil society (including non-government organisations) to accelerate the application of the Social Model nationwide, and regular disability awareness-raising efforts as mandated by the CRPD.

Indonesian PWD and the DPO, together with the government, policy makers, politicians, the mass media and civil society (including non-government organisations and university students) should initiate a stronger social movement to accelerate social inclusion and the establishment of legislation, similar to the disability rights movement in Great Britain and the United States (US) in the 1970s, which yielded the Disability Discrimination Act in Great Britain, and the American Discrimination Act in the US.

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memorandum



To	Associate Professor Fran Crawford and Ms Dini Widinarsih
From	Teena Bowman
Subject	Protocol Approval OTSW-13-2010
Date	1 July 2010
Copy	

School of Occupational Therapy and
Social Work

**Human Research Ethics
Committee**

TELEPHONE 9266 3600
FACSIMILE 9266 3636
EMAIL l.browning@curtin.edu.au

We are pleased to advise that your Application for Approval of Research with Minimum Risk for the project **Creating welcoming communities: Indonesian people with disabilities speak out** has been approved.

Approval of this project is for a period from **29 June 2010 – 30 June 2011**. If you have not completed your research by the expiry date, a new application must be submitted.

If at any time during this period changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise us immediately. The approval number for your project is **OTSW-13-2010**. Please quote this number in any future correspondence.

Please Note: The following standard statement must be included in the information sheet to participants:

This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning 9266 2784 citing OTSW-13-2010.

If you have any questions regarding the above, please do not hesitate to contact me.

Yours sincerely

A handwritten signature in blue ink that reads "Teena Bowman".

Teena Bowman
HDR Student Administrator
Centre for Research into Disability and Society
Curtin Health Innovation Research Institute
School of Occupational Therapy and Social Work



FACULTY OF SOCIAL AND POLITICAL SCIENCES
UNIVERSITY OF INDONESIA

KAMPUS UI, DEPOK 16424
PHONE : 7270006, 7872823, 7869785
FAX : 7872820, 7270007

Number : 540/PT.02.H4.FISIP/Q/2010
Re. : *Letter of Support*

TO WHOM IT MAY CONCERN

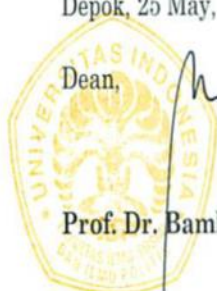
This is to acknowledge that **Mrs. Dini Widinarsih**, currently a Postgraduate Student at Curtin University of Technology, Australia, is our permanent lecturer at the Faculty of Social and Political Sciences, Universitas Indonesia. With regards to her Ph.D study, she proposes a research on disability issue under the title "Creating Welcoming Communities: Indonesians with Disabilities Speak Out".

Herewith, I would also like to express my support and agreement upon the research proposal to be conducted by the above name in partnership with the Centre of Disability Studies, Faculty of Social and Political Sciences, Universitas Indonesia.

I believe the research is of great significance towards the development of disability studies as well as the improvement of disability awareness among people, especially in the Indonesian society. I am also certain she would be able to accomplish her research with a fruitful outcome.

Depok, 25 May, 2010

Dean,



Prof. Dr. Bambang Shergi Laksmono, M.Sc.

APPENDIX C:
Notes of review of video from YouTube website

Descriptive Review of 30 Disability Awareness Videos from YouTube website

No	Title	Time	Year	Keywords	Producer & Origin	Summary	Category
1	Disability Awareness	0:30	2007	Blind –visual impairment	RAMF Center for Independent Living – Illinois, USA	Gardening activity of person with visual impairment	PSA
2	Rotary Nepal Disability Awareness Video : Blind –visual impairment	1 : 08	2009	Blind –visual impairment	Rotary Nepal & TRIFC (The Rose International Fund for Children	Rajesh Hamal-Nepali Film Star became a role model on how to help person with visual impairment crossing the street	PSA & Instructional
3	Rotary Nepal Disability Awareness Video : Shall we worship	1 : 09	2009	Physical disability- wheelchair	Rotary Nepal & TRIFC	Rajesh Hamal-Nepali Film Star became a role model on how to help person using wheelchair to access the steps in places of worship	PSA & Instructional
4	Rotary Nepal Disability Awareness Video : Hearing from Heart	1:06	2009	Hearing impairment	Rotary Nepal & TRIFC	Rajesh Hamal-Nepali Film Star became a role model on how to communicate with person with hearing impairment and how we can include ourselves in their lives.	PSA & Instructional
5	Living with Blindness, Day to day challenges in Nepal	1:13	2009	Blind –visual impairment	Rotary Nepal & TRIFC	Nirmala, Nepali with visual impairment, talks about how challenging her life as person with visual impairment who lives in Nepal	Personal story
6	Living with Disability in Nepal	3:28	2009	Physical disability	Rotary Nepal & TRIFC	Jamuna Subedi, Nepali with artificial limbs, told her life story thus losing both of her leg and her daily activity to use artificial limbs	Personal story

7	How I live with disability	8:02	2008	Physical disability	Personal (Anthony Bartl) - Australia	Anthony Bartl, Australian with quadriplegia showed his everyday life	Personal story
8	Living and overcoming life with disability	3:22	2007	Physical disability	Personal (Marty Sheedy) – USA	Marty Sheedy, American with arthrogryphosis/ scissor leg shared his everyday life	Personal story
9	Disability Awareness at UCM /University of Central Missouri, USA)	1:20	2009	Various disability (?) Accessibility	UCM – USA with support from Office of Accessibility Services - USA	Documentary of Disability Awareness activity in UCM on the occasion of Disability Month –every October	Documentary
10	Disability Awareness at Georgia University	5:32	2009	Wheelchair - sport	? personal documentary - USA	Dr Brenda Pitts made film project for cultural aspect of sport at master program, Georgia University which show participants who use wheelchairs playing basketball	Documentary
11	Disability Awareness at Marshal University	2:01	2009	Physical disability ; simulation	? personal documentary - USA	Documentary of Disability Awareness activity in Marshal University on the occasion of Disability Month where participant spend day either in wheelchair or sight impairment	Documentary
12	Disability Awareness Month	4:06	2009	Physical disability	? personal documentary - USA	Stephie, American who use electronic wheelchair showed her ability to swim and her social life .	Personal story
13	Disability Awareness	4:32	2009	? ? not clear	Personal (Tim Owen) - ?	Personal photos of Tim Owen with text made by him with the intention of helping people understand those have disability	? Personal story / documentary

14	Disability Awareness: Able to choose – on newsmaker	5 : 27	2009	Physical disability	'Able to Choose' Organization – Arizona, USA	Interview in TV show – Comcast Newsmaker with Lisbet Ward – person using wheelchair , who is the Virginia board for PWD education. The topic are support & choice for access to public service/transport	documentary
15	Everyday life for person with disability with personal assistance	10:00	2008	Physical disability	Danish & Bruger Fondation – Denmark	Documentary of several people with disabilities who have personal assistant in their everyday life in Denmark.	documentary
16	Citizen with disability navigate inauguration	2:14	2009	Physical disability	UPI.com	Personal struggle of Ben Spangenberg on his treacherous trip to the new US President, Barack Obama inauguration. He is in a wheelchair since He was born with Spina bifida.	Personal story & documentary
17	Living with Hearing impairment	2:26	2009	Hearing impairment	Get Reading company, UK	Reading Evening Post reporter, Natalie Slater finds how it feels living with a hearing impairment ie. Across the road, dealing with post office.	PSA / documentary
18	That's the normal thing to do	4:56	2009	?? not clear	Personal (Jean & Mike – Queensland, Australia)	Jean & Mike, the parent of Samantha-person with disability, share their experience about the practice of forced cotenancy by the Queensland,	Personal story
19	Think! A Wheelchair user's daily struggle	2:48	2009	Physical disability- wheelchair	Turning point production, USA	Personal struggles of Rosemarie Bruin on her visit to the local shop. She is a wheelchair user due to Spinal injuries she sustained many years ago.	PSA & instructional

20	Understanding visual impairment	3:05	2009	Visual impairment	Illustrstream Health, USA	Explanation about visual impairment and etiquette for empathetic & effective interaction with individual with visual impairment	Informational Instructional
21	Understanding hearing impairment	3:09	2009	Hearing impairment	Illustrstream Health, USA	Explanation about hearing impairment and etiquette for empathetic & effective interaction with individual with hearing impairment	Idem ditto
22	Understanding mobility impairment	3:05	2009	Mobility impairment	- " -	Explanation about mobility impairment and etiquette for empathetic & effective interaction with individual with mobility impairment	Idem ditto
23	Understanding wheelchair operation	3:09	2009	wheelchair users	- " -	Explanation about wheelchair operation and how to interact effectively with individual using wheelchair.	Idem ditto
24	Disability Awareness: high life	0:41	2003	visual impairment	Information TV – UK & www.disability.gov.uk	A Lady with visual impairment does her job in tour /travel agency satisfactorily. The message: "See the person, not the disability"	PSA
25	Disability Awareness: committee	1:00	2003	Physical disability- crutch	Information TV – UK & www.disability.gov.uk	PWD with crutches going to be communal committee. The message: "See the person, not the disability"	PSA
26	Disability Awareness: getting served	1:01	2003	hearing impairment	Information TV – UK & www.disability.gov.uk	A Man with hearing impairment does his job as bartender. The message: "See the person, not the disability"	PSA
27	Disability Awareness: 45 sec	0:50	2009	Physical disability	Szabist – Public Relation Project	A video clip which show that people often underestimated person with disability. It send	PSA

						message: We don't need your PITY ! We need respect!	
28	No Wheels...No works – part 1	7:00	2009	Physical disability-wheelchair	??	Documentary of wheelchair receiver, Juan Fransisco, in Cordoba. He is a traffic controller who earn \$ 8/day of which \$ 6 goes to taxi driver.	documentary
29	No Wheels...No works – part 2	5:55	2009	- " -	??	- " – The quality of video is poor, too noise	Idem ditto
30	Disability means possibility	0:46		- " -	Scope	Wheelchair user singing while waiting train.	PSA

* PSA : Public Service Announcement

* Yellow highlight mean the videos that used as sample to be watched by the Critical Reference Group (CRG) participants as discussion's trigger

Notification / Explanatory Statement

Appendix D has been removed by the author due to lack of permission.

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Notification / Explanatory Statement

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